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ABSTRACT

This report describes eight programs funded by the New York State Developmental Disabilities Council to provide training and assistance to parents who are developmentally disabled. The report is based on review of program and client records and interviews with directors, staff, and enrolled families. The first chapter provides an introduction to the study, its methodology, and limitations. Descriptive profiles of the programs, budgets, staffs, and their sponsoring agencies are presented in chapter II. Chapter III focuses on the families served and the services offered by the programs. Chapter IV addresses specific operational aspects of the programs, ranging from their admission and discharge criteria to their assessment and treatment planning practices to their relationships with local child protective and preventive services. Chapter V provides a summary of the directors', staff's, and recipients' assessments of the programs' effectiveness, as well as Commission staff observations of program strengths and weaknesses. The final chapter provides conclusions and recommendations which focus on the need for adequate funding, the role of enrolled parents in service planning, the need for program standards, and the need for required training programs for volunteers and paid staff. Letters related to the report are appended. (DB)

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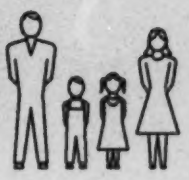

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Serving Parents Who Are Mentally Retarded: A Review of Eight Parenting Programs in New York State

New York State Commission on Quality of Care
for the Mentally Disabled

September 1993

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Serving Parents Who Are Mentally Retarded: A Review of Eight Parenting Programs in New York State

Clarence J. Sundram
CHAIRMAN

Elizabeth W. Stack
William P. Benjamin
COMMISSIONERS

September 1993

NYS COMMISSION
ON QUALITY OF CARE
FOR THE MENTALLY DISABLED

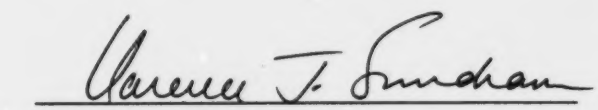
Acknowledgments

The Commission wants to express its deep gratitude to the families served by the eight parenting programs reviewed. Through their stories and experiences, recast and retold to protect their confidentiality in the vignettes in this report, the Commission was able to obtain a first-hand perspective of parenting with special needs that it would never have been able to construct from an empirical data base alone. The Commission is especially appreciative of the 25 families who invited Commission staff into their homes to meet their children and to learn more directly about their daily lives.

This report would also not have been possible without the gracious assistance of the program directors, parenting aides, and volunteers of the eight parenting programs reviewed. The dedication of these women and men in helping parents who are mentally retarded and in many cases in extending their workdays far into the night and weekends was remarkable across the programs. At each of the eight parenting programs, these individuals devoted considerable time from their busy schedules to accommodate our site visits and to share with us what they had learned about serving parents who were mentally retarded.

This evaluation study was funded by a grant from the New York State Developmental Disabilities Planning Council. Throughout the conduct of the review, the Commission has benefited from a discussion of the issues presented with the members of the Council.

The findings, conclusions, and recommendations expressed in the report reflect the unanimous opinion of the Commission.



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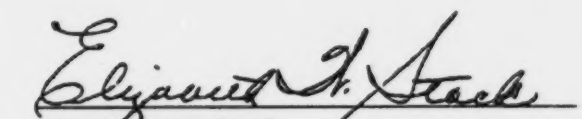

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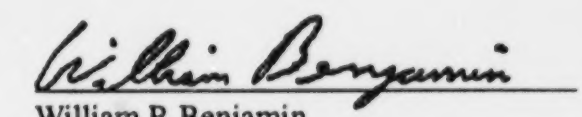

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- New York State Office of Mental Retardation and Developmental Disabilities
- New York State Department of Social Services
- New York State Office of Advocate for the Disabled

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Chapter I
Introduction

This report discusses eight programs, funded by the New York State Developmental Disabilities Council (DDPC), to provide training and assistance to parents who are developmentally disabled (Figure 1). The Council had initially requested that the Commission conduct a formal evaluation of these eight programs, all of which were originally proposed to rely on a common service delivery model, heavily reliant on "companions"—older persons volunteering as parent trainers for parents with developmental disabilities. The Commission's study of these programs, however, has taken a broader descriptive focus, as the Commission discovered that, within months of receiving their funding grants from the Council, each of the eight demonstration programs had tailored and substantially altered the initially proposed service delivery model.

In the conduct of this evaluation, the Commission also gathered substantial data on 54 families with one or more parents with significant cognitive limitations and/or developmental disabilities. Although this report presents a brief profile of these families, the Commission also prepared a more comprehensive report on the families studied, *Parenting with Special Needs: Parents Who Are Mentally Retarded and Their Children.*

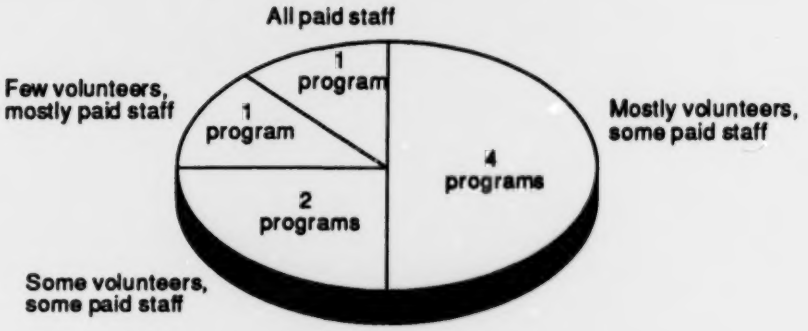
A Medley of Program Models

Although seven of the eight programs did use volunteers to assist in their work with families, only four relied primarily on volunteers, and one of these programs served only five families (Figure 2). Another one of these programs closed within the first year of operation. One program entirely abandoned the concept of utilizing volunteers before it even started delivering services; one other program used volun-

Figure 1: Funded Parenting Programs

- Parents with Special Needs
  Young Adult Institute
  New York City
- Parent Training Program
  Sinergia, Inc.
  New York City
- Special Needs Parenting Project
  The Task Force for Child Protection, Inc.
  Dutchess County
- Senior Companion Program
  Ulster County ARC
- Senior Companions/Parents with Developmental Disabilities Project
  Orleans County ARC
- Senior Companion Program
  Chautauqua County ARC
- In-Home Parenting Training Program
  Community Services for the Developmentally Disabled, Inc.
  Erie County
- Senior Companion Parent Training Program
  Heritage Centers
  Erie County

Figure 2: Program Reliance on Paid Staff Versus Volunteers (N = 8 Programs)



teers in only a very limited capacity, and usually not in the families' homes. Another two programs relied primarily on paid parenting aides, but had recruited several very capable volunteers who played integral service roles with some of the families enrolled.

Programs also differed substantially in the extent to which their families were served exclusively by the DDPC-funded parenting program or also referred to other services sponsored by their agency, including sheltered workshops, supportive apartments, early childhood programs, and Department of Social Services (DSS) funded case management. Similarly, some programs provided many more service referrals to other agencies in their community. Intensity of service provision from the demonstration programs themselves also varied extensively, ranging from only a few hours a week to a regular on-site home presence of 15 or more hours a week.

Finally, most of the programs were learning by doing, and as their programs moved forward, they continued to make changes in their service delivery model. These changes were often substantial, and they often directly affected the services the families received. Program directors were candid in acknowledging that in the first year they made many false starts; most had thoroughly redesigned many key aspects of their programs, from their parenting training sessions, to the training and direction they provided their paid parenting aides and volunteers. Thus, to a large degree, the individual service delivery models of each of the programs were also continually evolving.

A Descriptive Study

It soon became apparent that a formal evaluation was not well-suited to the heterogeneity evident in the eight demonstration programs, or to the changing nature of the programs' distinctive service models over their relatively brief two years of operation.

A formal evaluation study was also short-circuited by the absence of strong recordkeeping by the majority of the eight programs. None of

the eight programs had maintained good records of specific program accomplishments or the achievements and difficulties of the families they had served. Thus, programs could not report how many families, through their intervention, had obtained more appropriate housing, or conversely how many families, despite their intervention, had been evicted from their homes or apartments.

Programs also did not have records to substantiate the number of families which had graduated from the surveillance of local child protective or preventive services programs or which had been the subject of additional child abuse or neglect reports subsequent to their intervention. Indeed, directors of three of the eight programs intentionally shunned these hard measures of program success or failure, as they believed these measures would inaccurately overshadow the positive, if less quantifiable, day-to-day benefits of their programs for the families served.

With these limitations in mind, the Commission chose instead to provide a descriptive profile of the eight programs and the specific services that they offered to the families studied. This profile also includes self-assessment ratings of the programs' effectiveness provided by the program staff and volunteers and the families themselves. Additionally, reflective of a central mission of the programs to enhance the self-esteem of the parents, especially as related to their parenting, this descriptive profile includes a discussion of the parents' perceptions of the best and worst parts of being parents.

Methods

The Commission had the opportunity to access information about the programs from many sources (Figure 3). From the outset, the Commission was able to review the programs' initial grant proposals, and Commission staff were invited to attend two cluster meetings of senior staff of the eight programs sponsored by the Developmental Disabilities Planning Council. The Commission also reviewed fiscal reports prepared by the program staff, and later followed up with telephone interviews to obtain more detailed program funding information.

Figure 3: Review Methods

- ✓ Meetings with program directors
- ✓ Review of program proposals
- ✓ Review of program funding and staffing
- ✓ Two site visits to each program
- ✓ Record reviews and staff interviews for 41 enrolled families (initial sample)
- ✓ Modified Developmental Disability Profile of parents in 41 enrolled families (initial sample)
- ✓ Home visits to 25 enrolled families (second sample)

Commission staff also made two on-site visits to programs, one in the fall of 1991 and one in the spring and summer of 1992. Both visits focused on obtaining a front-line perspective of the day-to-day operations of the programs and the families they served. On the initial visit, Commission staff spent several hours speaking with program staff and reviewing the program records of a sample of 41 of the 86 families enrolled in the eight programs. Program staff were also asked to complete a slightly modified version of the Developmental Disability Profile (DDP), the official needs assessment of the New York State Office of Mental Retardation and Developmental Disabilities, for each of the parents in the 41 families.

On the second visit, Commission staff visited the homes of 25 enrolled families, accompanied by the parenting aide/volunteer assigned to the family. These 25 families included 12 families in the initial sample, plus 13 new families.[1] During the second site visit, Commission staff also met with the staff of the local departments of social services to obtain an understanding of how the programs interfaced with local child protective and preventive services.

Interview data with program staff and families, as well as record review and fiscal data, were collected on structured instruments.

Organization of the Report

A basic descriptive profile of the programs and their sponsoring agencies is presented in Chapter II. This chapter provides information related to the size and budget of the sponsoring agencies, the funding of the parenting programs, and the programs' staffing. Chapter III focuses on the families served by the programs and the services offered by the eight programs. Chapter IV focuses on specific operational aspects of the programs, ranging from their admission and discharge criteria to their assessment and treatment planning practices to their relationships with local child protective and preventive services in their counties/boroughs.

Chapter V, entitled "Measuring Program Success," provides a summary of the directors', staff's, and recipients' self-assessments of the programs' effectiveness, as well as Commission staff observations of their strengths and weaknesses.

Finally, in Chapter VI, the Commission attempts to distill some of the lessons learned as a result of this evaluation in an effort to assist the Developmental Disabilities Planning Council and the relevant state agencies and service providers in addressing the future needs of parents with developmental disabilities and the complex programmatic and funding issues inherent in doing so.

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[1] Although the Commission had hoped to make home visits to all 41 of the families in the initial sample, this was not possible. At the time of the follow-up visits, one of the eight programs had closed down operations, and staff of one other program steadfastly refused to allow any home visits. At the remaining six programs, there were also other sampling changes, as some of the initial families had dropped out of the program, and some families did not want the Commission staff to visit.

Chapter II
Programs and Sponsoring Agencies

As discussed in the introduction, the eight programs were more characterized by their variability than by their similarity. Not only did each of the eight programs make significant changes along the way in their operation, they also started with significantly different visions of what services they would provide and how they would serve families. The programs also ranged from small, informal operations to relatively large programs which received substantial agency and community resource support, apart from their funding grant from the Developmental Disabilities Planning Council.

The purpose of this chapter is to highlight the marked heterogeneity among the sponsoring agencies of the programs, as well as the funding and staffing of the eight parenting programs themselves. Although these resource differences alone did not shape the variability among the eight programs, the Commission did find that the size, experience, and resources of the sponsoring agencies did have a fundamental influence on the parenting programs.

The Sponsoring Agencies

All eight of the sponsoring agencies were established not-for-profit agencies, and seven (88%) were primarily focused on service provision to persons with developmental disabilities. Five of the eight agencies (63%) exclusively served persons with developmental disabilities.

The agencies also reflected a combination of smaller and larger agencies. One of the agencies sponsored only two other service programs in addition to the DDPC-funded parenting program, whereas three sponsored three to five other programs, and four were large agencies with six or more other programs. Total annual budgets of the sponsoring agencies of the eight programs also varied widely from $240,000 to $45,000,000. Three agencies had total annual operating budgets of more than $25,000,000; three had budgets between $10,000,000 and $15,000,000; and two had budgets under $2,000,000. (Figure 4).

Figure 4: Sponsoring Agency Budgets
(N = 8 Programs)

The sponsoring agencies also differed significantly in terms of their tenure as service providers in their communities and the strength of their relationships with other community service providers. Whereas all of the eight agencies had been operating for at least five years, four of the eight agencies' tenures in their communities had spanned more than three decades. Reflective, in part, of the size of their budgets and their tenure in their communities, several of the sponsoring agencies were also seen as critical service providers in their communities by others.

The Commission did not assess the relationship of these intangible experience and expertise variables to program success. It was apparent, however, that the manifold needs of many of the families often required many different types of services. Sponsoring agencies which could easily meet these needs, either through their own programs or through well-orchestrated referrals to other agencies in their communities, clearly had an initial advantage over smaller and younger organizations.

Program Funding

Commission site visits to the eight programs clarified that there was considerable variability in the funding bases of the eight programs. Differences in resources available for the parenting program were due, in part, to differences in the funding for the individual programs. More critically, however, a program's resources were dependent on what services it could readily access or share from its sponsoring agency.

For example, four programs had successfully accessed Department of Social Services Medicaid case management funds to cover many of these service costs for all or some of their families. Many programs also accessed some home health aide services for enrolled families, and one program had been able to access DSS-funded home health aides to assist several of its enrolled families for up to 40 hours weekly.

Three of the programs had also integrated their services to parents with developmental disabilities with the agencies' preexisting supportive housing and enriched foster care programs. In addition, at five programs, enrolled parents had easy access to the sponsoring agencies' supported work and sheltered work programs, and at two programs, many of the young children of the enrolled families had easy access to the sponsoring agency's early intervention preschool program. Most of the programs also shared transportation services with their parent agency.

Even from the narrow perspective of their direct parenting training and assistance service, *only one of the programs operated exclusively on its funding grant from the Council.* Several programs had received supplemental funding grants (usually under $25,000) from the New York State Office of Mental Retardation and Developmental Disabilities. These included grants under the Office's traditional family support services program, as well as other assorted purchase of service contracts for intensive parent training and individual support services. One program had received a small grant ($15,143) from the local United Way, and five of the seven operating programs reported making in-kind contributions to the parenting program ranging from $1,000 to $21,000.

Program grants from the Council also varied across the eight programs, ranging from $40,000 to $59,000 for the federal fiscal year 1992. In the spring of 1992, three of the programs also solicited and received a $25,000 supplement for crisis services.

As shown in Figure 5, the total funding for the programs did not always correlate to the number of families served or the intensity of services provided. In 1992, per family funding across the programs ranged from $4,670 to $10,710.

Future Funding Sources

All seven programs which continued operation after the first two years of funding from the Developmental Disabilities Planning Council hoped to find alternate funding sources to maintain their programs subsequent to the end of their third year of demonstration funding from the Council. The seven programs pinned their hopes on a variety of different funding sources, with most programs counting on putting together a funding package from several sources.

Figure 5: Total and Per Family Funding by Parenting Program*

Program	*Total Parenting Program Funding*	*DDPC Grant Award*	*Total Families Enrolled*	*Per Family Funding*
Orleans County ARC	$126,180	$70,000	27	$ 4,670
Sinergia, Inc.	$104,000	$84,000	18	$ 5,770
Young Adult Institute	$ 96,429	$75,000	9	$10,710
Heritage Centers	$ 55,555	$50,000	5	$ 8,890
Community Services for the Developmentally Disabled	$ 71,429	$50,000	11	$ 6,490
Chautauqua ARC	$ 71,000	$50,000	10	$ 7,100
The Task Force for Child Protection, Inc.	$ 56,143	$40,000	10	$ 5,610

* All funding information is based on program self-reports for fiscal year 1991-92, with the exception of Heritage Centers, which is based on a 15-month period. Enrollment information is based on self-reports of enrolled families as of fall 1991. Funding information for Ulster County ARC is not included, as this program closed in December 1991.

Two programs hoped to continue funding the services to their enrolled families by integrating the services of their parenting program with other agency family support, residential, and/or early intervention programs. Four programs indicated that they would look to the Office of Mental Retardation and Developmental Disabilities' various ongoing grant programs for continued funding, including its family support program and its newly established individual support services program. Three programs also spoke of seeking funding from their local departments of social services as a preventive service program, while three mentioned that they were seeking private funding sources, including private foundation funding and funding from the recently established Self-Advocacy Association.

At the time of the Commission's interviews with the program directors in the fall of 1992, however, none of the seven programs were clear on the availability of continued funding, and only a couple of the programs had formally pursued the potential future funding sources that they had identified.

Program Staffing

At the time of the Commission's fall 1991 visits, all but one of the programs had only one or two paid full-time equivalent staff persons. As a matter of practice, this meant that most of the

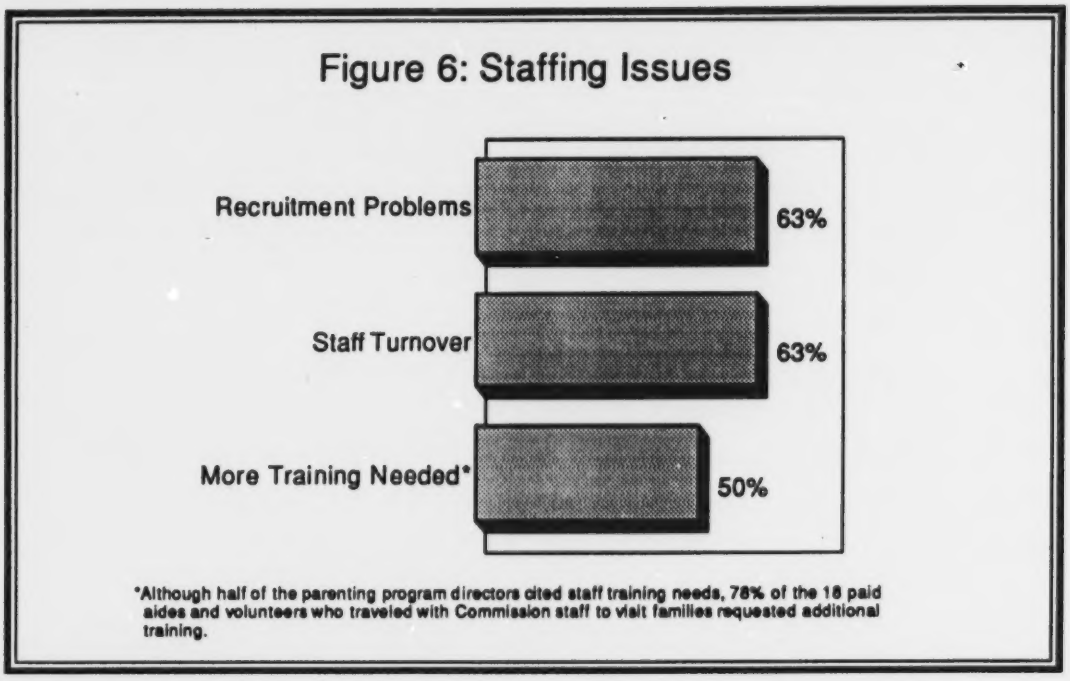


Figure 6: Staffing Issues
Recruitment Problems
63%
Staff Turnover
63%
More Training Needed*
50%
*Although half of the parenting program directors cited staff training needs, 78% of the 18 paid aides and volunteers who traveled with Commission staff to visit families requested additional training.

programs were staffed with a program director and either one or two part-time or full-time parenting aides.[2] One program, which relied extensively on additional funding sources, stood apart from the other programs with seven paid staff persons.

As noted above, in the spring of 1992, three of the programs requested and received additional funding ($25,000) from the DDPC to augment their staffing with either a part-time or a full-time paid crisis worker. These programs presented a coordinated request to the Council, stating that so many of their families were in periodic crisis that they required a special staff person to cope with these recurring situations.

With the exception of one program, all programs reported having at least one volunteer at the time of the Commission's fall 1991 visit. Two of the programs had only one volunteer; two had two volunteers; and three had four volunteers. The latter programs relied primarily on volunteers to provide direct services to families. One of these three programs served only five families, and one other program, although relying heavily on volunteers to provide in-home support and training, also placed approximately half of its enrolled families in enriched family foster care homes.[3]

Staff Qualifications and Recruitment

Five of the eight programs (63%) reported encountering some problems in recruiting paid staff or volunteers, and four of these programs (50%) reported that recruitment problems were frequent (Figure 6). Part of this problem was

[2] All paid staff figures reflect full-time equivalent staff positions. Volunteers, on the other hand, usually work 10-20 hours a week.

[3] Through these foster family placements, this program had essentially ensured round-the-clock supervision and support for half of its families, thus obviating some of the more serious flaws of the volunteer service delivery model cited by other programs choosing not to rely so heavily on volunteers in serving families.

clearly linked to the wages the programs were paying. In accordance with the federal guidelines, volunteers earn only $2.35 an hour, and to enroll in the program, volunteers also needed to meet certain low income qualifications. The paid parenting aides were also not usually well paid. At some programs, hourly wages only slightly exceeded the minimum wage, and at none of the programs did paid parenting aides earn more than $6.50 an hour.

More than money, however, program directors reported that recruitment was difficult because this job was not for just anyone. When asked what qualities they looked for in their paid staff and volunteers, program directors were remarkably consistent. Across the programs, three factors—acceptance of persons with developmental disabilities; receptiveness to new ideas; and interest, knowledge, and confidence in childcare and parenting activities—were cited as the most important staff qualifications. When asked to select adjectives that more broadly described their most effective staff and volunteers, program directors offered "responsible," "self-confident," "compassionate," "motivated," "nonthreatening," "accepting," "flexible," and "patient."

Figure 7: Parenting Aides and Volunteers Talk About Their Work Experiences

Best Part

Watching a mom learn something we've been working on and seeing her actually do the task.

Seeing parents accomplish tasks and be happy with themselves. Seeing real bonding occur between mom and child.

Seeing her child progress with his speech and the progress the mother has made to get custody of her son.

When I first met the 18-month-old child, she had no affect and needed affection. It was a great joy to see her running into her mother's arms to be picked up and watching her grow to become responsive.

Seeing the parents hit the children less and talk with them more.

[Knowing] the mom is able to shop better and make better choices.

Worst Part

Not being able to help the children and protect them from harm, particularly with parents who should not have custody of their children.

Adolescent problems, since the child goes beyond parents intellectually.

Parents' mismanagement of money, domestic violence, and poor housekeeping skills.

Families not following through with suggestions, hard to see if I make any difference. Many times I want to throw my hands up in the air.

When a parent was charged with child abuse/neglect.

Parents need to interact more with their children; they don't follow up and complete assigned tasks.

As suggested by the above, program directors had high expectations of their volunteers and paid aides. At the same time, relatively few of the paid staff or volunteers had any formal education or training in the field of developmental disabilities, and very few had actually worked with persons with developmental disabilities in the past. It seemed to be more important that the individuals be people who saw themselves as having something both to give and to learn and who had a genuine commitment to and interest in working with adults with developmental disabilities as they strived to parent their children.

Staffing Turnover

Although each of the programs reported spending considerable time recruiting and screening potential job candidates, most had also experienced significant paid staff and volunteer turnover. Volunteer retention, especially, appeared to be a problem for most programs. At the time of the Commission's fall 1991 visit, the seven programs using volunteers had a total of 17 volunteers on their staff. Only two of these programs reported no volunteer turnover in the past year, while five others reported having lost a total of 12 volunteers in the past year. Although most of the volunteer turnover was due to voluntary resignations, two of the programs had terminated a volunteer in the past year.

When Commission staff visited families in their homes with the parenting aides and volunteers, they came to appreciate more fully the difficult and stressful jobs aides and volunteers had undertaken. At many programs, paid aides and volunteers had given families their home phone numbers, and after-hours crisis calls for assistance were frequent.

Most paid staff and volunteers also had at least one family on their caseload which was resistant to suggestions for parenting or simply unable to carry them out consistently. These families and their frequent crises placed enormous stress on paid staff and volunteers who worried about the well-being of the children and/or the parents. And, despite the deep gratitude of many of the families for the services of the parenting program, paid aides and volunteers recognized that there were many pressing needs of the families that they were unable to meet.

As shown in Figure 7, interview comments of paid staff and volunteers vividly portrayed the ups and downs of their jobs. Their comments reinforced that these were not jobs for men or women who expected quick rewards and few disappointments. At the same time, they also reinforced the substantial and invaluable rewards that these jobs could offer.

Training and Supervision

All eight programs reported having an ongoing in-service training program, and all but one of the programs reported having a formal orientation program for new volunteers and paid parenting aides. As shown in Figure 8, these programs covered an array of topics. Some focused specifically on the needs of persons with developmental disabilities, but more centered on basic skills and information about childcare, health, and nutrition.

Weekly direct supervision of volunteers and paid staff was also the general rule, although one program, which relied heavily on students and persons with other day jobs, reported that face-to-face supervision sessions were sometimes held only on a monthly basis.[4] Most of the

[4] Subsequent to the Commission's on-site visit and report to this program, its director reported that supervision of paid parenting aides has been enhanced.

Figure 8: Training Topics for Parenting Aides and Volunteers

- Specific parenting skills
  - infant care
  - nutrition
  - budgeting
- How to engage and interact with the families
- How to detect abuse, neglect, and domestic violence
- How to handle specific situations

programs, however, scheduled one full or half-day each week when all volunteers and paid staff met to discuss the families served, the problems encountered, and needed revisions in the families' services. At several programs, these sessions were also regularly coupled with an in-service training presentation.

Notably, despite the regularity of in-service training, program directors at half of the programs reported that more training would be helpful. Subsequently, when the Commission staff travelled with the 18 parenting aides/volunteers to visit the 25 families in their homes, an even more striking 78% of the aides/volunteers stated that they would benefit from additional training.[5]

[5] These 18 individuals included 12 volunteers and 6 paid parenting aides.

Chapter III
Getting Started and Serving Families

With the exception of one program which had been providing training and assistance to parents with developmental disabilities for at least five years, none of the programs found smooth sailing in their early months of operations. From finding good staff and volunteers to keeping parents motivated to designing (and redesigning) their service delivery to meet the families' needs and interests, start-up problems were the rule, not the exception, across programs.

Most programs also came to find their enrolled families more needy, and often less trusting, than they had initially anticipated. In particular, many families had serious difficulties related to poverty, family dysfunction, alcohol abuse, and domestic violence, as well as their cognitive impairments. Maintaining the trust and confidence of parents, as well as their interest and commitment to making fundamental changes in their lives, surfaced as paramount issues for many programs.

Finally, within weeks, programs learned that their responsibilities for many of their enrolled families would span far beyond providing parenting training and assistance. For many families, programs had to start with the basics of finding appropriate housing, ensuring that the food supply was adequate, and meeting basic medical care needs. Parenting aides and volunteers also became far more than teachers and role models for many families where they became the family's one true friend and the family's vital ambassador with social services caseworkers, teachers, doctors, and public health nurses.

Start-Up Delays

Although each of the eight demonstration programs officially received its first funding grant from the New York State Developmental Disabilities Planning Council in September 1990, actual start-up dates and family service initiation dates for the eight programs varied substantially. While some of the agencies had historically served some of these families, as the parents and/or children had been served in one of their other sponsored programs, with the exception of one agency, the Council grant marked the initiation of the agency's focused attention in serving this population. Not surprisingly, some agencies experienced more difficulties and delays in getting this new venture started than others.

Six of the eight programs (75%) reported that they did not begin serving families until four months after the program had opened its doors, and two of these programs reported that they did not begin serving families until more than six months after they opened.

Delays in beginning service delivery were attributed to different problems. One program had problems identifying families in need of its services, while all had some problems maintaining families in their programs. Five programs also reported that they initially struggled to recruit volunteers, and three determined after several months to rely more intensively on paid parenting aides. Several programs also encountered some initial problems in matching families and parenting aides/volunteers. And, while all programs had some problems in retaining families in services, for two programs, this issue had a substantial impact on their early operations.

Families Served

In the fall of 1991, a total of 86 families were being served by the eight programs. The re-

Edward and Charlene G.

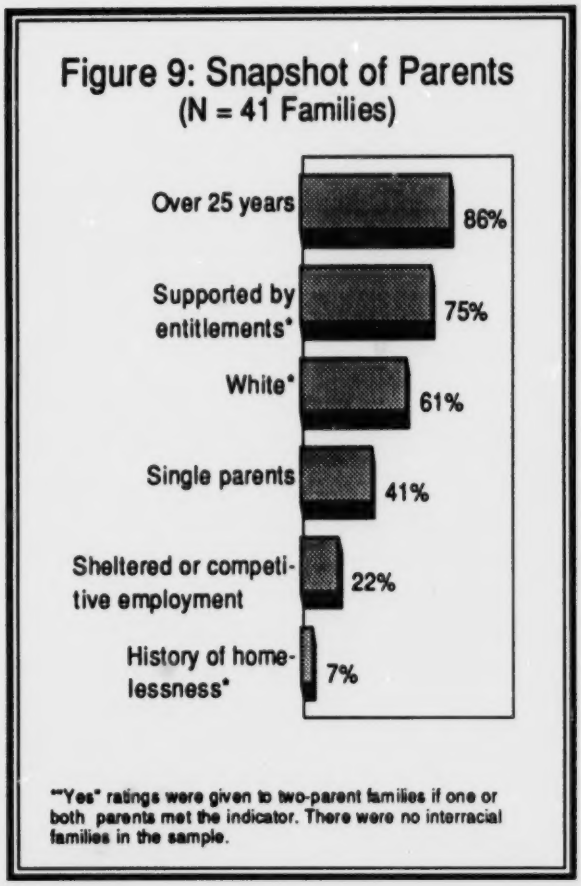
Mr. and Mrs. G. met each other at the state institution where they both lived until they were 22. They have two children, Patrice, age 4, and Gerald, age 2. Mrs. G. also has a 20-year-old daughter from a previous marriage, who visits often and helps around the house.

This family lives in a residential neighborhood in a very clean three-bedroom apartment. They have all the modern conveniences, including a microwave, several television sets, a VCR, a dishwasher, and a coffee maker.

Both Mr. and Mrs. G. are mildly mentally retarded, and Mr. G. has an ambulation problem and uses a cane. Mrs. G. works full-time at a nursing home, where Mr. G. also volunteers two mornings a week. They are very supportive of one another and share in caregiving for their children and in all the household chores. They can become easily overwhelmed, especially when one parent has to care for both children at the same time. In the evenings, Mr. G. prepares dinner for the family, and the family often visits other extended family members who live in the community and provide considerable support.

Mr. and Mrs. G. have been enrolled in the parenting program for slightly more than one year, and the volunteer, who spends about eight hours a week in their home, reported that the family is doing well. Although Patrice is learning disabled, the volunteer stated that she is a smart and outgoing child who enjoys painting and drawing and likes to be the center of attention. Her younger brother, Gerald, has been diagnosed as mildly mentally retarded, with a slight speech impediment, but he is reportedly doing very well at the preschool program that he is attending. The volunteer described Gerald as a happy, well-adjusted boy.

The volunteer told the Commission that Mr. and Mrs. G. can well manage most of the household chores, cooking balanced meals, and attending to the children's medical and dental needs. He is focusing his time with the parents in encouraging them to be comfortable with and a little less protective of the children, particularly in allowing the children to play with appropriate toys, crayons, coloring books, etc. This is very difficult for Mr. and Mrs. G. who fear that if something happened, their children would be taken away.



ported capacity of the eight programs ranged from 5 to almost 30 families. Six of the eight programs, however, were quite small, serving fewer than 15 families. Half of the programs reported being capable of serving 5-10 families; two reported capability to serve 11-15 families; and two reported capability to serve 16-27 families.

Despite their start-up problems, by the fall of 1991, six of the eight programs were also full, and five of these programs (63%) had at least one family referral pending. One program, which had experienced especially difficult start-up problems, was serving only two families (capacity five families); one other program which had made the decision to close in a few months was also serving only two families.

In the fall of 1991, the Commission visited the eight programs and obtained demographic, clinical, and social history data on 41 enrolled families. These data allowed us to develop a snapshot profile of the families served. A brief summary of this profile is provided here, but readers are referred to a more comprehensive description of the families in the Commission's companion report, *Parenting with Special Needs: Parents Who Are Mentally Retarded and Their Children.*

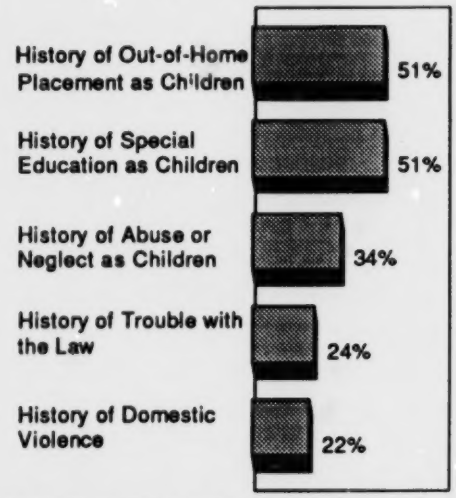
The Parents

Parents ranged in age from 19 to 54, but three-fourths were between the ages of 25 and 40. Most of the families were headed by two parents, but 41% were single-parent families. Over half of the families had only one or two children, but 17% of the families had four or more children (Figure 9).

The families served by the eight programs were also largely poor; almost all families (regardless of size) subsisted on less than $900 per month. Many of the families had lived or now live in substandard housing. Although the parenting programs had helped many of the families move to more suitable apartments or homes, most families continued to live in cramped arrangements or in housing that was difficult to heat or that needed some maintenance work.

For many of the parents, their own childhoods had been marked by abuse or neglect and/or out-of-home placements and, unfortunately, these histories followed many of the parents into adulthood. Almost half of the families had had at least one child removed from their custody, at least temporarily, due to allegations of abuse or neglect, and histories of domestic violence and trouble with the law were common to approximately one-fourth of the families (Figure 10).

Figure 10: Social Histories of the Parents*
(N = 41 Families)

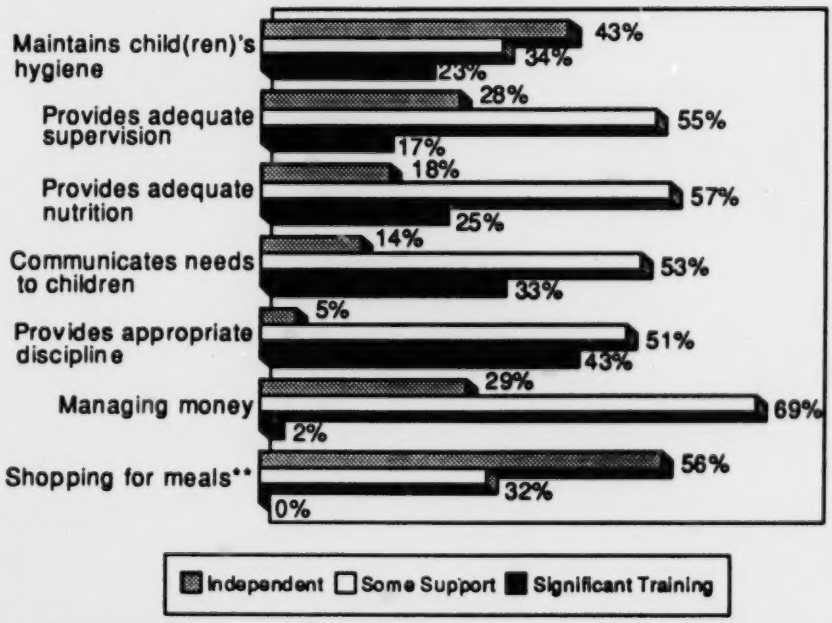


*"Yes" ratings were given to two-parent families if one or both parents met the indicator.

Although few of the parents had a physically handicapping condition, almost all were labeled mentally retarded, one-third had a significant medical condition, 22% had a known alcohol or drug abuse problem, and 20% had a diagnosed psychiatric condition. Finally, program staff reported that over half of the parents had behavioral problems, sometimes ascribed to their developmental disability, ranging from tantrumming to being verbally abusive or physically assaultive.

Most of the parents were characterized by program staff as independent in most personal care daily living skills and as competent in basic adult literacy skills. In contrast, however, few of the parents demonstrated independence in many basic parenting skills, including childcare supervision, medical care follow-up, shopping for and cooking nutritionally balanced meals, providing appropriate discipline, and money management (Figure 11).

Figure 11: Level of Parenting Skills*
(N = 41 Families)



*In two-parent families, ratings reflect performance of most capable parent.
**Totals do not sum to 100% for this category due to "unknown" responses.

The Parents Speak Out

A more personal perspective of the parenting experience was voiced by the parents themselves. During home visits with 25 families, Commission staff first asked, "What was the best part of being a parent?" As illustrated in the parents' comments below, most parents answered simply, but eloquently, that their joy in parenting came from loving and caring for their children.

. . . taking care of my children, playing with them, teaching them.

. . . loving [my son], watching him sleep.

. . . sharing time with my children.

. . . everything, my whole life revolves around [my son]. I want to give him a better life.

. . . taking the children to the park.

. . . being responsible for the children and preparing the proper foods.

. . . everything, being a family and having a lot of responsibilities.

On the flip side of the coin, the parents' comments on the difficult parts of being a parent showed an equally honest appraisal of their frustrations, fears, and insecurities.

. . . making sure my child is okay and safe, watching her, making sure she is not sick.

. . . knowing he's getting older, and it will be harder to parent.

When the kids get sick, [I am] not sure what to do.

. . . everything, having kids is the most difficult. Keeping the kids or my husband from getting to me.

In the evening when I'm alone with all four kids at home, trying to feed them, get them ready for bed, and take care of the [infant] twins.

. . . the 24-hours-a-day taking care of them, especially all the doctors' appointments.

It's hard to keep up with them; discipline is hard. They won't share. It is hard for my husband.

. . . having to repeat myself and having to hit the children.

. . . trying to make [my son] behave. I'm afraid he will love his aunt more than me. I'm also afraid he will be taken away.

I find it hard to be patient. I don't like to get up early. [My daughter] is bad sometimes. [My son] likes to cry.

As reflected in these comments, the parents with mental retardation enrolled in the parenting programs shared many of the mixed feelings of all parents. They spoke freely of their love of their children and how dear their children were to them. They also voiced common frustrations about the full-time job of parenting, with its pleasant and less pleasant tasks and its rewarding and unrewarding moments.

A striking feature of the parents' comments was also their reflection of the parents' perceptiveness of their limitations and fears. In visiting with the families, Commission staff rarely met parents who did not explicitly reference their difficulties and limitations and their awareness that these problems placed them in ongoing jeopardy of losing the custody of their children. The parents' recognition that their job would become increasingly difficult as their children grew past toddlerhood and entered school was particularly noteworthy.

Karen S.

Ms. S. is 27 years old, she is legally blind, and she is the mother of four children, 6-year-old Michelle, 18-month-old Joey, and 5-month-old twins, Patty and Peter. None of the four children are disabled, although Michelle was held back in first grade because of problems with reading.

As a child Ms. S. was abused, and throughout her adult life she has had a tendency to form unstable and often violent relationships with men. Her current boyfriend Mr. J. is the father of three of her children. Mr. J., who has a history of mental illness and substance abuse, has had serious problems with the law involving time in jail, and he has been accused of physically abusing both Ms. S. and the children.

Just prior to the Commission's review, local child protective services had sustained an allegation of physical abuse against Mr. J. Reportedly, Mr. J. was drunk and kicked Ms. S. while she was holding one of the twins, causing her to drop the infant who sustained bruises.

Subsequently, the local child protective services limited Mr. J.'s visiting privileges and restricted him from the home after dark or overnight. Parenting program staff report that Mr. J. is rarely in the home, but when he is, he is usually under the influence of drugs and alcohol.

This family of five lives on approximately $650/month. Their three-bedroom flat was clean at the time of the Commission's visit, but it needed a paint job and the furnishings were tattered and worn. Although the older children were not at home, Ms. S. and the twins were nicely dressed in clean and well-fitting clothing.

Ms. S.'s parenting aide visits four times a week, spending five hours each day assisting with housekeeping, cooking, shopping, personal hygiene, and child care. The parenting aide also accompanies Ms. S. on appointments and errands. Since enrolling in the parenting program, staff report that Ms. S. has gained skills in using public transportation, caring for her children, and keeping her apartment clean. Since the twins were born, the parenting program has also arranged for Joey's enrollment in a free day care program for six hours each weekday. Ms. S. has also joined a domestic violence support group, but she is not always able to attend its weekly evening meeting, as she has no one to watch the children.

Michelle, the 6-year-old, is also a big help with household chores, taking on much more than one would normally expect of a child her age. Staff of the parenting program, however, are concerned that Michelle has no outside activities (except school) and that she has no friends.

Ms. S. is very committed to the parenting program and recognizes that she could not manage without its assistance. She was especially appreciative of the help in keeping her house clean, babysitting for the twins, and transporting the children to clinic appointments. Ms. S. told the Commission that the best part of parenting was "loving her kids."

The Children

The vast majority of the children of these families, who remained in their parents' custody, were 10 years old or younger, and nearly half (49%) were 3 years old or younger. A high percentage of these children, especially those over 2, have been identified as having at least one disability or limitation, ranging from mental retardation (24%) to learning disabilities (21%) to emotional disorders (11%) to physical handicaps (9%) (Figure 12).

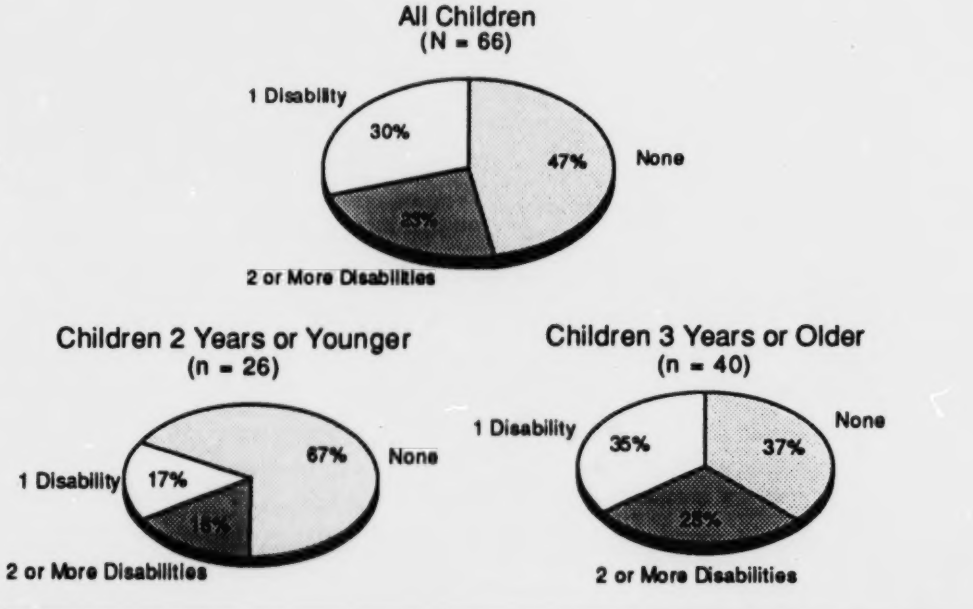
Although a majority of these children have come to the attention of their local departments of social services, often due to a past allegation of abuse or neglect, reports of the parenting program staff indicated that most are now doing fairly well. For example, according to program staff reports, most children were receiving nutritious meals, appropriate medical and dental care, proper attention to their dress and hygiene, and adequate supervision and discipline.

Notwithstanding this observation, however, on many basic indicators of custodial care, protection from harm, school performance, and adaptive behavior, approximately one-fifth of the children evidenced significant problems (Figure 13). Difficulties in getting to school appropriately dressed and groomed, keeping up with their school work, and making and keeping friends, as well as unspecified "behavioral" problems, were especially common among the children.

High Turnover in Enrolled Families

Almost all programs also reported a significant turnover in the families served, which they largely attributed to families dropping out of the program rather than "graduating." In total, the eight programs reported that 36 families had been "discharged" in the past year. Relating this number of discharged families to the current

Figure 12: Disabilities of Children at Home



Lori and Vincent A.

Mr. and Mrs. A. are both developmentally disabled, and they have been married for ten years. Mrs. A.'s 15-year-old son, Louis, who is moderately mentally retarded, lives with them in a small public housing apartment in a New York City neighborhood, which was characterized by Mrs. A. and parenting program staff as unsafe and drug-infested.

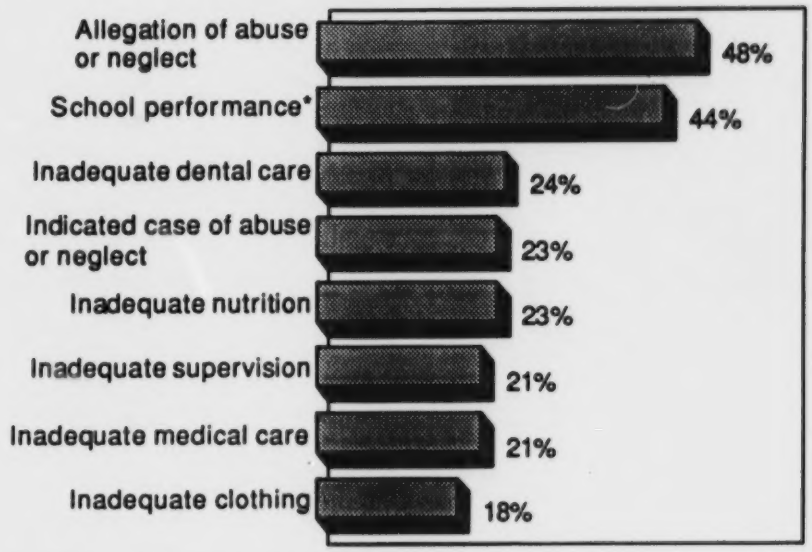
Mr. A. has worked for the City for 15 years. Mrs. A. stays home, often visiting her mother, who lives in the same building and helps her with laundry and shopping. The parents have been cited for neglect of Louis many times in the past, and their referral to the parenting program was triggered by the City's Child Welfare Authority. Apparently, officials from Louis's special education class had raised several concerns about his arrival at school in dirty clothing and with poor hygiene.

The parenting aide provides four hours of weekly in-home service (the maximum offered by the program) to the family. Initially, the parenting aide assisted in cleaning the family's apartment which was filthy and roach-infested. Recently, she has established a chore schedule for the family, in the hopes that they will maintain the apartment themselves. The parenting aide is also helping Mrs. A. with personal hygiene care for Louis and with managing her time and money. The parenting aide reported that some progress has been made, but the parents continue to have difficulty ensuring their own and Louis's medical care needs, making their income stretch to cover their needed prescription medicines, and keeping up with basic housekeeping.

According to the parenting aide, life for Louis has not been easy. School officials report that he has many difficulties getting along with other children, in part, because he is often ridiculed for his unkempt appearance and odor. Outside of attending school, Louis rarely leaves his apartment during the week, as his mother fears for his and her safety in the neighborhood. Louis does attend a structured recreational program a few hours each Saturday.

At the time of the Commission's visit, Mrs. A. spoke earnestly about her desire to find more social opportunities for Louis and of her need for respite. Mrs. A. told the Commission that she "wants to give [Louis] a better life." She also added that parenting was very hard, "I do not have any time to myself, to do the things I want to do."

Figure 13: Difficulties of the Children
(N = 66 Children)



*Based on 34 children in sample enrolled in preschool or public programs.

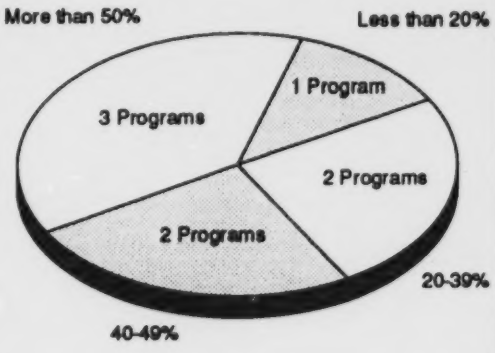
total enrollment of the programs in the fall of 1991 (86 families), the Commission calculated an average discharge dropout rate of approximately 42%. As shown in Figure 14, however, family dropout/discharge rates for individual parenting programs ranged from 15% to 63%.

Half of these families (50%) reportedly were discharged because they were "resistant" or "noncompliant" with the offered services. These general terms usually meant that the parents were often not at home when the aide/volunteer made scheduled visits, that the parents were noncompliant in ensuring that their children received needed medical care or proper nutrition, or that the families were simply uncomfortable having program staff intrude into their lives. Another 22% of the families were discharged reportedly because they "did not like the program" (11%) or because they had lost the custody of their children (11%). Another 11% of the families were discharged because they had moved. The remaining six families stopped participating reportedly due to transportation and other personal problems.

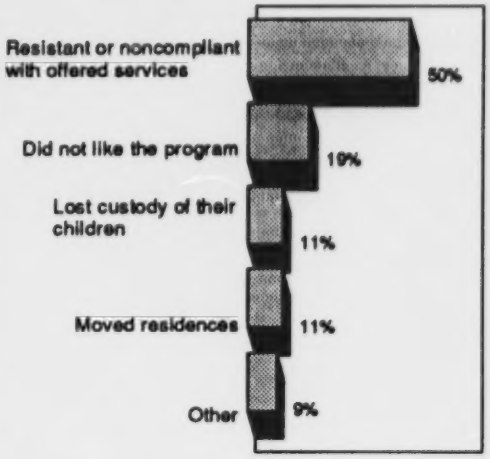
All of the eight programs reported that they followed up with the families who withdrew from their programs, and seven of the eight reported trying to encourage these families to re-enroll. Further discussion, however, revealed that programs often had few follow-up avenues open to them, as the parents usually did not want program contact. Most of the program directors affirmed that keeping the front door open for these families, when and if they returned, was often the most substantial assistance that they could offer.

Most program directors reported that, when warranted, they did notify local child protective and/or preventive services that a family had

Figure 14: Annual Discharge/ Drop-Out Rates* (N = 8 Programs)



Reasons Why Families Dropped Out (N = 36 Families)



* Annual rates calculated based on total program enrollment in fall of 1991.

dropped out of the program. Making this decision, however, was clearly not easy for staff at most of the programs, who feared that such notification would permanently damage any trust the family may have had with the program and preclude the likelihood that the family would ever willingly reenroll. Staff at two of the programs reported less ambivalence with this decision, as they believed that a mandated approach to parenting training was more effective for some families.

Basic Program Services

All programs offered home visits to enrolled families, and all of the programs provided an off-site parenting class, usually paired with a social activity. At all but two of the programs, off-site parenting classes were held weekly. At the remaining two programs, classes were scheduled biweekly or once a month.

Attendance at off-site parenting classes was not "required" at any of the programs, however, and in practice, attendance tended to be irregular, with the vast majority of families missing at least one weekly class a month. At the time of the Commission's observation, attendance at most programs was less than 60% of the enrolled families, and staff at most programs acknowledged that only about half of their enrolled families were "very committed" to the parenting class.

Each of the programs also provided an array of services targeted to basic daily living assistance, including transportation, help with shopping and money management, assistance in following up on medical care, including transportation to doctor appointments and liaison services between the family and the doctor. Since most of the families had very young children, all of the programs also provided focused assistance in infant care and basic child development. For families with school-age children, all but one program also provided liaison services with the school.

Virtually all of the programs also found that they spent considerable time working with their local department of social services, both on fiscal entitlement and on child protective and

preventive services issues. The prevalence of mental health and alcohol and drug abuse problems in the families also brought most of the programs in close contact with these service providers in their communities.

Service Intensity

Despite this thematic consistency in the nature of the services offered by the programs, there was significant variation in the intensity of the services rendered. At one of the programs, there was a standard rule that each family would receive only four hours of service weekly, regardless of need. In contrast, at two other programs, most families received more than 15 hours of in-home service each week.

The average family in the Commission's initial sample of 41 families was receiving nine hours of service weekly, whereas the average family in the second sample of 25 families was receiving seven hours of service weekly. As shown in Figure 15, in both samples, approximately one-third of the families were receiving five or fewer hours of service weekly from the parenting program, and less than one-fifth were receiving more than 15 hours of service weekly.

The two samples differed markedly, however, in the number of hours of service offered to families in between these two extremes. In the first sample, 24% of the families received 6-10 hours of service weekly, and 17% received 11-15 hours of service weekly. In the second sample, 60% of the families received 6-10 hours of service weekly, but no families received 11-15 hours of service weekly.

It was difficult for the Commission to understand all of the variation in service provision across the families enrolled. Some percentage was obviously linked to the needs of the families. For example, families without transportation or access or ability to use public transportation often received more services simply because the aide or volunteer became the family's lifeline to stores, doctors' appointments, recreation, etc. Similarly, in some families, parents or children had significant medical care needs which required regular monitoring and frequent doctor visits.

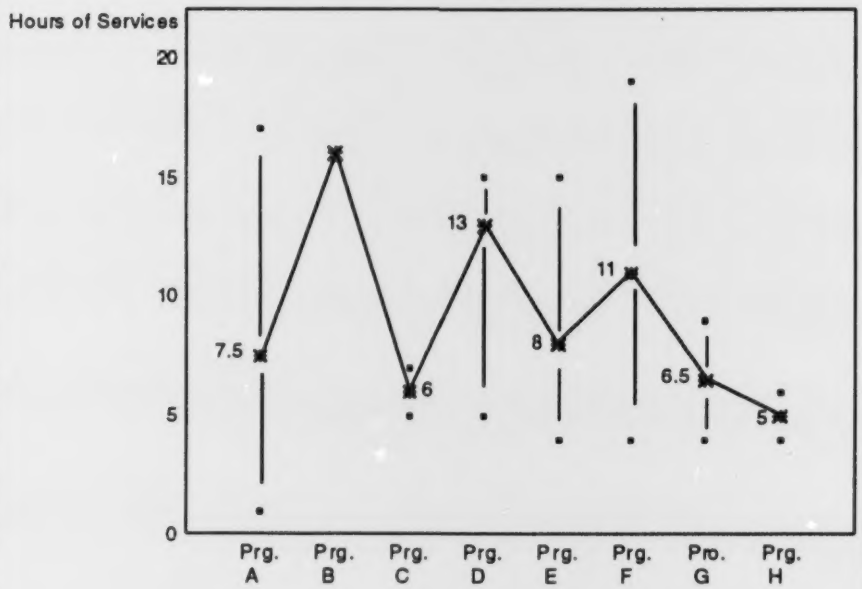
Needs-based rationales seemed, however, to explain the variations within parenting programs better than those across parenting programs. As mentioned above, all of the families in one program were receiving only four hours of services weekly, and these families were among the least likely in the sample to also be receiving DSS case management services or home health aide services. In contrast, at another program many of the families enrolled were living in supportive apartments or special foster care homes, receiving 15-20 hours of in-home service weekly from the parenting program, and in some cases, also receiving more than 20 hours of home health aide service weekly. In comparing the families served by these two geographically proximate programs, there were no obvious differences to justify the wide discrepancies in the services provided.

Aside from agency and program resources, the Commission discovered that family interest and acceptance of offered services also had a significant influence on the services it received. In many cases, program staff reported that they would have liked to provide more services or to enroll the parents or children in other agency or community programs, but that one or both parents resisted.

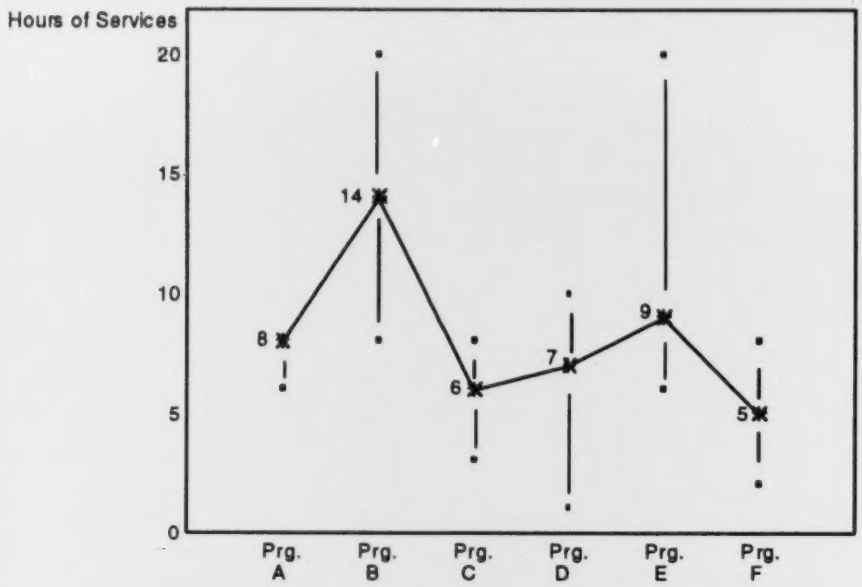
Successes and Obstacles

In traveling with the aides and volunteers to visit families at home, Commission staff asked each of the 18 individuals where they felt they had achieved success relatively easily with the families they served and where they felt they had encountered formidable obstacles. Although these reports are anecdotal, they do provide some interesting insights.

Figure 15: Service Provision by Program
(Hi, Low, Mean)
Initial Sample
(N = 41 Families)



Second Sample
(N = 25 Families)



- Represent the hours of services received by the most intensively served and the least intensively served family sampled.
- ★ Represents the hours of services received by the average family sampled.

Aides' and volunteers' reports of successes included:

. . . is more capable of cleaning her home; she has learned to be patient with her child; she takes more care in personal hygiene, and she has learned to cook.

. . . has learned how to deal with the kids; they are wild.

. . . has learned to make eye contact with her children and to praise them when they do a good deed.

. . . has learned to channel anger in different directions, and she has increased her knowledge of good nutrition and diet.

. . . doesn't lose patience with her child as quickly; she is able to follow through with suggestions.

Aides and volunteers were also not reticent, however, in articulating the sometimes formidable obstacles they encountered in working with some families.

. . . [helping] mothers overcome their possessiveness of their children and their fear of losing them.

. . . helping parents maintain a safe environment for themselves and their children.

. . . working with mothers who are resistant to new ideas and husbands who sometimes interfere.

. . . getting mothers to stop overfeeding their children junk food and to be patient with their children.

. . . getting husbands to trust the aide and the program.

. . . addressing differences in parenting styles.

. . . teaching discipline.

. . . coping with the disappointment when parents do not attend to their children's needs.

Unmet Service Needs

All of the program directors were also vocal in their acknowledgment that they were not able to meet all of the needs of their enrolled families, either with the parenting programs, other agency-sponsored programs, or other community services. Most wished simply for more hours in a day or more hours of staff time to spend working directly with individual families.

The comments of volunteers and paid aides who travelled with Commission staff to visit the families reinforced the many needs the program staff believed they could not address.

I would like my caseload to be smaller so that I can spend more time with the families.

I am unable to do [what needs to be done] with a caseload of eight families who are very involved and needy.

The program didn't give me enough information on the families' problems and what I was up against. I could use more hours with the families.

We should have two volunteers visit a family together.

We need respite services.

The most common unmet need cited across all parenting programs was the need for social activities for the parents and the children. For many of the parents, the parenting classes and the parties held three or four times a year by the parenting programs were the extent of their social life. And, in most of the families studied, the children had few friends and rarely had a friend over to play or went to a friend's house to

Stacy and Brian O.

Mr. and Mrs. O. are a married couple in their 30's with a 2-year-old daughter, Patty. This couple met while living in separate group homes, where they continued to live after Patty was born. Initially, Patty was placed in foster care, but eight months later, when a supportive apartment became available, she moved in with her parents.

Mrs. O. is a homemaker and cares for Patty, while Mr. O. works full-time as a maintenance person and part-time at McDonald's. Both parents are mentally retarded, and Patty is presently being evaluated for developmental delays, as she rarely speaks and is unable to perform simple tasks.

Mr. and Mrs. O. are very committed parents who regularly attend parenting classes, and they recognize and appreciate the many supports and services provided to them. A volunteer senior companion visits twice weekly (each time for three hours) and assists the parents with housekeeping, cooking, sewing, parenting skills, budgeting, and medical care follow-up. A homemaker, funded through the local social services department, also provides services to the family each weekday, 9 a.m.-5 p.m. (40 hours a week). According to the parenting program staff, the homemaker assists with many of the same tasks as the senior companion, but she is more likely to simply do the task for the family, rather than to take time to teach Mrs. O. how to do the task herself.

In addition to these services, Patty is attending a local Head Start Program, and a Head Start staff person works with Mrs. O. on appropriate stimulation and developmental play activities. Mr. and Mrs. O. also benefit from supportive families, with both sets of grandparents, as well as aunts and uncles, visiting often. They are also involved in the church choir and a Bible study group.

Although Mrs. O. still requires supervision and training in conducting many daily living tasks, including attending to Patty's medical needs, staff reported that Mrs. O. has made progress in learning how to clean, cook, prepare nutritious meals, and bathe her daughter. During the Commission's visit, Mrs. O. stated that the best part in being a parent was that she "enjoys having a baby" and that the most important thing the volunteer senior companion has done is "teaching me to bathe Patty." Mrs. O. is also learning functional vocabulary words from watching Sesame Street with her daughter.

According to all involved with Mr. and Mrs. O. and Patty, the parenting program and other support services are "the best things that could have happened for this family." The senior companion notes, however, that Mr. and Mrs. O. will probably require the assistance that they receive now for many years to come.

play. Staff at many programs spoke of the social isolation of the families they served, and the marked benefits they accrued simply by making friends.

Program staff reported that 73% of the 41 families in the Commission's initial sample and 72% of the families in the second sample of 25 families had at least one unmet service need. Other commonly cited unmet needs included help with cooking, money management training and assistance, tutors to help children with homework, and shopping assistance.

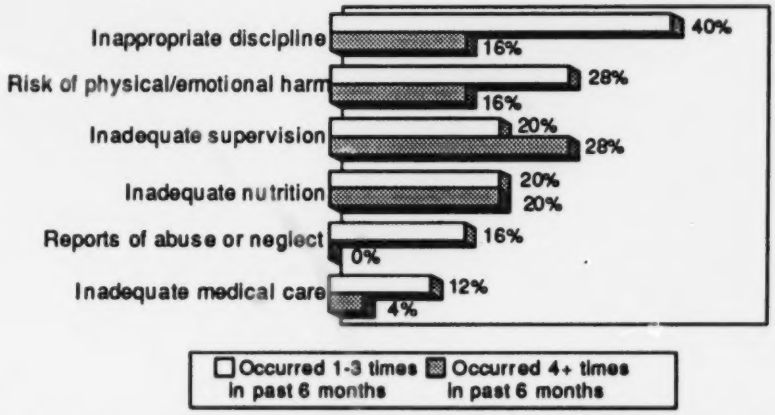
Chapter IV
Program Standards

Characteristic of the eight programs' variability in other respects, the Commission found little consistency among them in terms of their basic program standards. In fact, most of the programs operated with very few written standards. Instead, these programs, exempted from any state-mandated regulatory standards, largely relied upon informal guidelines for basic aspects of their operations, including admission and discharge criteria, treatment planning and progress reviews, and assurances for internal agency oversight.

While this reliance on informal program standards was understandable in view of the demonstration nature of the parenting programs and their temporary funding, it also led to marked differences among programs and few explicit expectations for quality control and risk management. These limitations took on special importance to the Commission as program staff candidly shared the high risk of child abuse and neglect for many of the families they served.

As mentioned in Chapter II, almost half of the sample families had at least one child removed, at least temporarily, due to an allegation of abuse or neglect. And, at the time of the Commission's fall of 1991 visit, 41% of the 41 sample families had at least one child who was currently placed out-of-home. Perhaps most relevant, parenting aides and volunteers indicated that children in 44% of the 25 families visited by the Commission had been at risk of emotional or physical harm at least once in the past six months, and that 16% had been at risk of such harm *four or more* times in the past six months (Figure 16).

Figure 16: Safety and Well-Being of Children in Families Visited
(N = 25 Families)



*The risk reports were made by the parenting aides/volunteers who accompanied Commission staff on home visits to the 25 families and who had been providing in-home and other direct services to the families.

These data findings highlight the high risk management needs of the parenting programs studied, and strongly suggest their need for a strong and accountable system of program operations which incorporates an effective system of risk management.

Admission Criteria

Seven of the eight programs visited reported that they had formal admission criteria for the parents enrolled. These admission criteria were also remarkably consistent (i.e., the parent must be developmentally disabled, 18 years of age, and willing to receive services), but it was also apparent that most programs were less than rigorous in applying them.

Early on in the Commission's visits to the eight programs, it became evident that they were serving a heterogeneous group of parents, some of whom appeared much higher functioning than others. While in each family studied at least one parent was significantly cognitively limited, whether these limitations had resulted in sufficient functional deficits to meet the federal or state criteria for classification of developmentally disabled was not clear.

As a matter of practice, only one of the eight programs reported trying to ensure formal psychological assessments of all enrolled parents. Many relied on psychological assessments conducted years ago; other programs relied on a parent's prior enrollment in special education as an indication of a developmental disability; and still other programs simply enrolled all families with functionally impaired parents whom they believed their programs could help.

For many parents, program directors were uneasy about forcefully pushing for formal psychological assessments. Many programs reported that their enrolled parents had eschewed the label of mental retardation most of their lives, and they would be reluctant to join any program that was targeted only to individuals who were mentally retarded or developmentally disabled.

Discharge Criteria

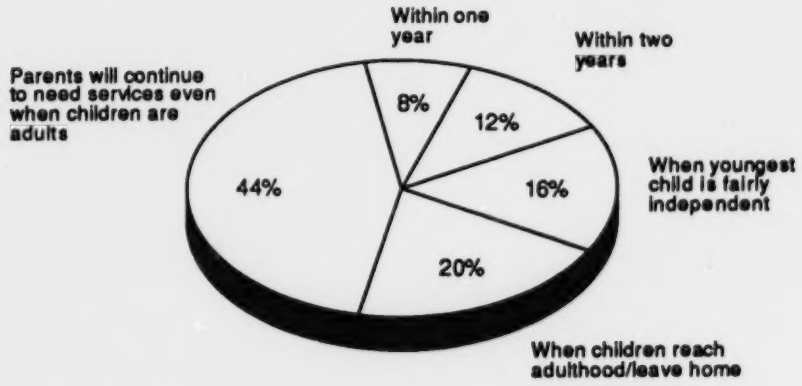
Five of the eight programs reported having formal discharge criteria. For most families, however, "discharge" was a matter of personal choice, and a program's discharge criteria were usually only a formality. Formal criteria across these five programs justified discharge both if a family had achieved all relevant parenting objectives and if a family was being significantly resistant or noncompliant with services.

In practice, however, most programs reported rarely terminating families for noncompliance; rather, these families usually simply stopped coming. Some families also left the programs (voluntarily) when all of their children were removed by child protective services.

Program staff were also candid in acknowledging that the vast majority of their enrolled families would require services for years, as their fundamental cognitive limitations would not change. Simultaneously, program staff explained that the parents' training needs would persist, and in most cases become more complex, as their children became older and the demands and tasks of parenting changed.

When making home visits, the Commission staff specifically asked aides and volunteers for estimated "graduation" dates for the 25 families. They reported that only 2 of the 25 families (8%) were likely to graduate within a year and that 3 others (12%) may graduate within two years. In contrast, aides and volunteers felt that nearly two-thirds of the families (64%) would need help at least until their children were grown or had left home. For nearly half of the families (44%), aides or volunteers opined that the families would need help even when the children were grown or gone (Figure 17).

Figure 17: Estimated Program Graduation Time Frames for Families (N = 25 Families)



*Estimated graduation time frames were provided by the parenting aides/volunteers who accompanied Commission staff on home visits to 25 enrolled families.

Treatment Plans and Progress Reviews

Seven of the eight programs reported preparing individual treatment plans for their enrolled families. Upon inspection, however, only two programs prepared plans which included goals accompanied by objectives written in sufficiently explicit terms to allow for a clear evaluation of the families' progress. More typically, treatment plans listed very generic goals and objectives (e.g., Ms. C. will learn to prepare fresh food; Ms. D. will budget for her needs; Mr. and Mrs. P. will manage their time, etc.), which targeted general areas for training or assistance, but did not clarify any readily measurable desired change in performance.

In reviewing the records of the 41 families in its initial sample, the Commission found treatment plans present for 28 families (68%), and plans for only 22 (54%) of the families included reference to specific parenting objectives.[6] (Figure 18).

Additionally, for most of the families studied, treatment plans did not appear, in practice, to be the primary guide for the day-to-day interventions between program staff and the families. For most families, these interactions were determined primarily by a pressing practical need of the family (e.g., transportation to the doctor, resolving problems with local social services, buying food, etc.), and, in some cases, by fairly regularly emerging crises that required immediate attention (e.g., the family had been accused of child abuse or neglect, the electricity was turned off, the police were called due to a domestic argument, etc.). Although aides and volunteers spoke of general issues that they worked on with individual families (e.g., ad-

[6] Commission staff were not permitted to directly review records of five of the sample families, all served by one program sponsored by a local Department of Social Services. The director of this program acknowledged, however, that comprehensive treatment plans were not usually prepared.

Deidre and Kevin O.

Mr. and Mrs O., who are both in their late 30's, have been married for ten years, and they have a 4-year-old daughter, Denise, and a 3-year-old son, David. Both parents share in household and childcare responsibilities, and neither works outside of the home. Denise began kindergarten in September 1992, and David will be enrolled in Head Start when he turns 4.

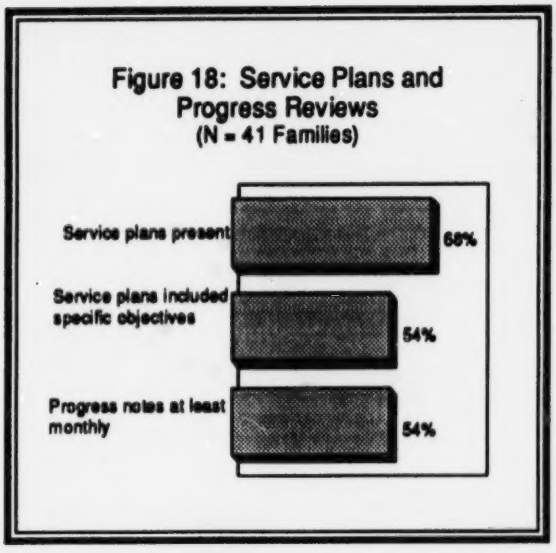
The family resides in a two-bedroom apartment. At the time of the Commission's visit, the apartment had been tidied, but it needed a thorough cleaning, and roaches were an apparent problem. According to the parenting aide and Mr. and Mrs. O., the children tend to be hyperactive, running around the apartment and jumping on the furniture. Denise also has some more serious behavior problems, including frequent tantrums and cursing and occasionally hitting other children and adults.

Mr. and Mrs. O. enrolled in the parenting program about a year ago, and they receive approximately four hours of in-home services weekly. To date, the parenting program has focused on helping the parents prepare nutritious meals, discipline their children effectively, and in making regular eye contact with the children when speaking to them.

This family also receives many hours of extended family support each week. Mr. and Mrs. O. receive a great deal of support from their parents, who provide financial assistance and help with childcare tasks. Mrs. O.'s grandmother and aunt also live in the same apartment building, and they, too, frequently stop in to help.

Ms. O. spoke up quickly when Commission staff asked what was the best part of being a parent, "I like being responsible for the children and preparing the proper foods." Mr. O. said he enjoys the "senior role." Although Mrs. O. could not think of anything that she dislikes about parenting, Mr. O. stated, "[I don't like] having to repeat myself and having to hit the children."

The parenting aide spoke positively about this family's progress since enrolling in the program and their long-term ability to elude any involvement with child protective services. At the same time, the aide felt that the parents would continue to need support services for many years to come.



dressing discipline more consistently and calmly or teaching basic cooking and shopping skills, etc.), almost all aides and volunteers stated that this was a job where one needed to do what called out to be done first and to follow the prestated treatment plan second.

In this regard, it is important to reemphasize that aides and volunteers, especially in programs which afforded ten or more hours of service weekly, had often become far more than teachers for the families they served. They were mentors, case managers, friends, and vital life lines to services and crisis resolution. They did what needed to be done, when it was needed or as they could make their resources stretch to do it, and periodically they met with their supervisors to reassess how their actual activities meshed with the prepared treatment plan.

Progress Notes and Evaluations

The Commission understands this common sense approach to service delivery, which appeared to meet the practical and most imperative needs of the families and to make allowances for the almost always tight resources of the parenting programs. At the same time, however, this approach also made explicit evaluations of a family's progress or lack thereof difficult to assess or document. Progress notes, when they were present (and three of the eight programs had almost no notes whatsoever in the records), usually described home visits and other staff activities, but rarely directly related to treatment plan objectives, except in general terms. Similarly, none of the programs prepared summary progress reports which explicitly identified skills or competencies where parents had shown improvement, developed mastery, or had shown no progress.

Interviews with directors of the eight programs indicated that all had some schedule for formally reviewing a family's progress, but the frequency of reviews varied widely. Only one program director (13%) reported consistently conducting reviews at least monthly; three (38%) reported holding reviews quarterly; two (25%) reported holding reviews semiannually; and two (25%) reported holding reviews annually.

Record reviews by Commission staff also suggested that routine progress assessments for many families were not based on a documented record of events or improvements over time, but rather on the more subjective cumulative verbal assessments of program staff. For 19 of the 41 families (46%) in the Commission's sample, records did not include even monthly progress notes. In addition to the absence of monthly progress notes, these records usually included very little information, if any, on the family's history, initial needs assessments, the parenting program's contacts with the family, the services rendered, or the specific problems the family was encountering. The scant record notes were particularly problematic in view of the staff/volunteer turnover of many programs. When a staff person/volunteer left and a new person took over, there was often little written history of what had been done, what had worked, etc.

It appeared that, in the absence of standards for the nature of treatment plans or their regular monitoring, the parenting programs had developed a system that worked well for them as they

Beth J. and Paul S.

Ms. J. and Mr. S., who are both mildly mentally retarded, live with their three children, Steven, age 4, Adam, age 3, and Timothy, age 2. This family was having marked difficulties at the time of the Commission's review. Local child protective services had been involved with the family long term, and the volunteer, who spends only three hours weekly serving the family, admitted to being overwhelmed with the family's needs.

The family lives in a three-story walk-up apartment in an old, run-down apartment building. The apartment's back door exits onto a porch, with insecure, waist-high railings and an open stairway with no door or gates. At the time of the Commission's visit, the landlord was repairing the central heat, and an unprotected space heater sat in the middle of the living room in easy reach of the family's young children.

At the time of the Commission's visit, the apartment was very dirty, with piles of laundry, garbage, and soiled diapers on the floor. Dishes were piled high in the sink, and flies were feeding off the food on the kitchen table. Some of the furniture was broken, and the living room couch was soaked with urine. Although the apartment has four bedrooms, one bedroom was being "repaired," toys were stored in a second bedroom, the parents slept in a third bedroom, and all three children slept in the fourth bedroom. There was no furniture in this room, except two mattresses which were on the floor, and it had no working light.

Although the volunteer had informed the family that Commission staff would be visiting, only Mr. S. was home when we arrived, but he was interested in talking. When asked what he likes most about being a parent, Mr. S. said, "I don't know, but I love my kids." Mr. S. also affirmed, "I don't hit my kids." He did note, however, that parenting was sometimes difficult, and that the children are very active and they fight with one another. He added that parenting Adam is especially difficult as he "is hyper and tells us he hates us and doesn't want to live here anymore."

The volunteer spoke openly about her frustrations with the family and her fears for the safety of the children. She noted that it was particularly frustrating, since neither Ms. J. or Mr. S. were very consistent in following up on her recommendations, especially in maintaining some order in the apartment.

sought to meet the immediate needs of families on a day-to-day basis, often with limited resources. What was lacking, however, was some other formal mechanism which programs could use to objectively evaluate the progress that families were making and specifically their attainment of skills, competencies, and behaviors which ensured the proper nurturing, well-being, and safety of their children.

Relationships with Local Child Protective/Preventive Services

More than half of the enrolled families in the eight programs had some current or recent relationship with their local child protective or preventive services. In addition, some families also had some other regular contact with their local department of social services around issues of fiscal entitlements, request for emergency funds, etc. In a significant minority of the families studied, the family had also either been mandated or recommended to participate in the parenting program as a result of a referral from their local social services department.

Thus, as a matter of common practice, at almost all programs visited, program directors, as well as parenting aides and volunteers, had ongoing contact with local social services officials. Most programs had also found themselves in the difficult position of having to contact the Child Abuse Hotline with an allegation of abuse or neglect about one of their enrolled families. Despite their frequent interaction, however, parenting program staff and local social services staff were not always in concert as they worked with the enrolled families, and many of these interactions were defined by informal and unwritten procedures.

On the one hand, parenting aides and volunteers sometimes felt that the child protective or preventive caseworkers simply did not understand the parents they served or their need for clearer and more patient instruction and assistance. In some cases, parenting program staff saw the protective and preventive workers as bureaucrats with checklists to evaluate the parents and their homes, but with little ability or time to teach or to help. One program staff person, for example, spoke with dismay about the preventive worker who drove a mother to the market to shop, but sat outside in the car, instead of going inside the market with her to help her buy appropriate foods.

On the other hand, there was also an almost inherent tension between the two staffs, as the parenting program staff came to be recognized as the "good" case managers who helped families out of crises and the child protective and preventive workers came to be inevitably seen as the "bad" caseworkers, who threatened to remove the family's children unless specific changes or improvements were promptly made. Some programs visited spoke positively of this dichotomy in the roles of the two family workers, pointing out that the warnings of the protective or preventive workers were often much-needed catalysts to prompt the parents to respond to recommendations that they were making. Others were less comfortable and noted that it would be more helpful if both caseworkers collaborated more, sharing the workload and ensuring consistent direction and support to the parents. Reflective of these varying points of view, some programs visited were relieved when their local child preventive services would terminate families once they enrolled in the parenting program; others saw this termination as an unwarranted break in services, more determined by a desire to reduce the county's child protective/preventive services caseload than any assurance that the child(ren) was no longer at risk. This ambivalence was also reflected in program staff's personal assessments of their local child protective/preventive services.

Of the 18 parenting aides or volunteers who traveled with Commission staff to visit the homes of the 25 families in our second sample, 7 had

Anne T.

Ms. T. is 27 years old, and she has four children, Marjorie, age 8, Calvin, age 7, Jimmy, age 4, and Larry, age 2. Marjorie has been placed in foster care, but the other three children live at home with Ms. T. and her boyfriend, Mr. V., who is Jimmy's father. Both Ms. T. and Mr. V. are mildly mentally retarded, and both have a history of mental health problems and alcohol abuse. Both have also been subject to several reports of alleged abuse of the children, and their relationship is disrupted by periodic domestic violence.

According to the parenting program staff, despite their intervention, circumstances are not usually good in the household. Ms. T. typically spends her mornings in bed, allows the older children to do what they want, and leaves the baby alone. The children are also usually poorly groomed and often dirty. Staff also reported that Ms. T. has regular problems assuring her children a nutritious diet or proper medical care. Although Ms. T. has extended family members in the area, they are reportedly not a good influence. Staff reported that her sister often takes her money and that her brother is currently in jail.

All of the three children at home have also had their personal difficulties. Calvin, age 7, has been classified as learning disabled. He has behavioral problems in school, which include frequently hitting other children. Diagnosed as mentally retarded, Jimmy, age 4, was recently the alleged victim of a child abuse report filed by program staff when they noted unexplained burn marks and welts in the shape of a hand print on his body.

The youngest child Larry, age 2, spends his day at home, but the parenting program staff are attempting to enroll him in an early intervention program, which they hope will compensate for the limited stimulation he receives from his mother. A little more than a year before the Commission's visit, Larry, too, was the victim of child abuse. Reportedly, Larry's father (who no longer lives in the household) broke Larry's arm in three places when he would not stop crying.

Despite its many problems, Ms. T.'s family receives only seven hours of in-home service weekly from the parenting program. Although the program would like to offer more services, their resources are limited, and Ms. T.'s willingness to have a parenting aide in the home more often is also questionable. Although the family is on the rolls of the local child protective and preventive services, the parenting program staff reported that these case managers have very limited contact with the family.

contact with their local child protective services and were willing to offer specific satisfaction ratings of the services they received. Approximately one-half of these aides/volunteers indicated they were "very satisfied" (29%) or "satisfied" (29%) with these services. In contrast, however, 43% indicated they were "dissatisfied" and supplemented their assessment with specific reservations about available services (Figure 19).

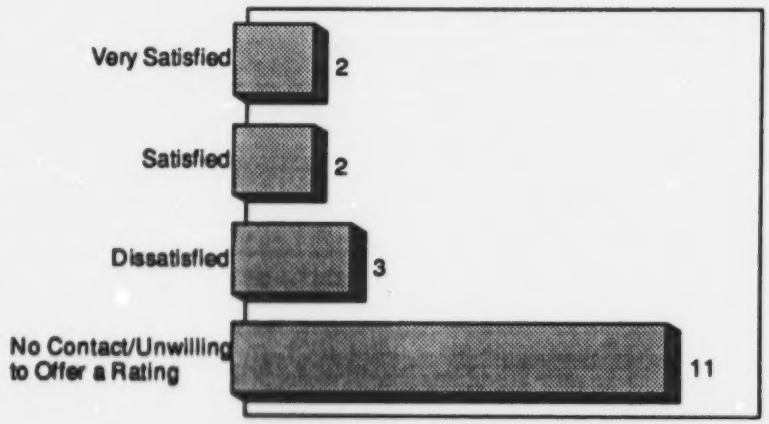
When to Call the Hotline?

Each of the eight programs also had its own usually unwritten protocol for determining when to contact child protective or preventive services or the Hotline on behalf of individual children. Although all programs reported that, when warranted, they would contact the Hotline, at all programs, making a call to the Hotline was viewed as an absolute last resort which would likely irrevocably damage the parent's trust in the parenting program staff. Three programs went further, reporting that they believed they could assist enrolled families best by avoiding, whenever possible, being identified with local child protective or preventive services. Each of these three programs kept very sparse progress notes, in part, according to the program directors, to ensure that their records would not be subpoenaed in child protective cases.

At all but one of the programs, the Commission came to learn about at least one family where one or more young child(ren) appeared to be in significant jeopardy of serious harm, either because of neglectful nutrition, medical care, and/or supervision. Although these families represented a minority of the families served by any one of the programs, their circumstances raised concerns. In discussing these families with the parenting program staff, Commission staff tried to understand why Hotline calls had not been made.

In many cases, we learned that the family was already on a child protective and/or preventive services caseload and had an assigned caseworker and that the parenting program staff assumed this caseworker would take care of any needed reports. In most of these instances, there

Figure 19: Parenting Aide/Volunteer Satisfaction with Local Child Protective/Preventive Services
(N = 18 Aides/Volunteers)*



*These 18 aides/volunteers accompanied Commission staff on home visits to the 25 families.

Andy and Patricia D.

Mr. and Mrs. D. are both mentally retarded. Mr. D. also has a long history of alcohol and drug abuse. At the time of the Commission's visit, the couple had three children, Douglas, age 5, Janice, age 4, and Billy, age 2, and they were expecting their fourth child. Mr. and Mrs. D. also had one child who reportedly died of sudden infant death syndrome. All three of the children have been diagnosed as learning disabled, and Billy has also been diagnosed as mildly mentally retarded, with a tendency toward head banging.

This family was referred to the parenting program by the staff of the sponsoring agency's early intervention program which two of the children attend. Early intervention program staff reported that the children often missed the program and that when they attended, they wore ragged, inappropriate clothing and had very poor personal hygiene.

Since enrolling in the parenting program, Mrs. D. has made some improvements in getting the children off to school and in attending to their personal hygiene. Although Mr. and Mrs. D. are only marginally committed to the parenting program, they have reportedly formed a good relationship with their volunteer who spends four hours a week in their home and an additional three hours each week observing the children in preschool. A primary treatment goal for Mrs. D. is to learn to engage in playtime activities with her children.

Parenting program staff acknowledged that despite some progress, things are still very unsettled in this family and that the appropriate nurturing and safety of the children is not always assured. Another major issue is Mr. D.'s continued and virtually daily abuse of alcohol and/or illegal drugs, often with his family members, who reportedly always stop in and "party" when the family's entitlement check arrives.

was regular verbal (usually telephone) contact between the parenting program staff and the protective/preventive worker assigned to the family, although these communications were rarely committed to writing.

In other cases, parenting program staff reported that in the recent past they or others had made many calls to the Hotline about the family for similar incidents to no avail and that they had come to understand that the Hotline just would not respond to this type of report.

Finally, in some cases, it seemed that the parenting program had simply worked with the family, going from one crisis to another, with no clear time intervals for evaluating progress and/or making the difficult decision that the parenting situation may not be resolvable. In the interim, it was not so much that the parenting program decided not to call the Hotline or to make a more formal report to its local child protective or preventive services about the family, as that it simply never stopped long enough to consider this alternative.

Through these discussions with staff at the parenting programs, the Commission came to appreciate more fully their difficulties in making a decision to call the Hotline and the intervening circumstances which affected their decisions. At the same time, however, in the absence of formal risk assessments of children at regular intervals, some formality in contacts and written communication between program staff and local child protective and preventive services staff, and a clear understanding of staff's legal reporting responsibilities to the Hotline, some required reports to the Hotline either were not made or were made late by the programs, leaving children at unnecessary risk of harm and serious injury.

Agency Oversight

Throughout the Commission's review of the parenting programs, one fact stood out from the very beginning—the sponsoring agencies, program directors, staff, and volunteers were very committed to the programs and the families they served. In all cases, sponsoring agencies also took on these programs largely to meet a visible unmet need in their communities, not because resources had become available to serve this population. One way or another, with direct matching funding and/or by borrowing from services of their other programs, all of the sponsoring agencies had made substantial funding commitments to the programs.

Thus, all of the sponsoring agencies had a substantial investment in the parenting programs, and their successes and work with the enrolled families was a subject of agency interest and involvement. At the same time, however, the Commission generally found little formal agency oversight of the parenting programs, which also enjoyed the status as an uncertified program from the Office of Mental Retardation and Developmental Disabilities, free from state oversight and regulation. In some cases, serious incidents which occurred in families were reported and reviewed by the agency's incident review committees, but this was not usually the case, as family incidents usually occurred when no program staff were present and had no connection with the parenting program.

Meetings with senior agency staff to review particularly problematic families or to review whether Hotline calls or child protective/preventive contact should be made were not regularly scheduled at any of the programs. Similarly, senior agency staff provided no regular oversight of program decisions about how to follow up with high-risk parents who terminated their program enrollment or whether to notify child protective or preventive services. Periodically, all program directors discussed these types of decisions with senior agency staff, but in almost all cases, it was incumbent on the director to initiate these discussions, which were not regularly scheduled. There was also no regular oversight by the sponsoring agencies' board of directors at any of the programs.

In questioning this lack of sponsoring agency oversight of the operations of the parenting programs, the Commission is not implying that most programs were operating poorly. Although in three cases the Commission noted problems in the daily operation of the parenting programs which clearly warranted senior agency staff intervention, in most cases these programs were being run very capably and competently by their program managers. Nonetheless, these programs clearly presented enormous risk management issues for even the ablest program managers and staff. Additionally, as noted above, the program staff inevitably became very personally involved with the families they served. In these situations, it is always helpful to have an independent third party, who is not so personally involved, reviewing decisions.

Chapter V
Measuring Program Success

As noted in Chapter I of this report, objectively measuring the success of the eight programs in meeting the needs of parents with developmental disabilities and their children is difficult for a number of reasons. The eight programs differed significantly in the services they provided and the resources they had available, confounding evaluative comparisons across programs. The absence of good recordkeeping by almost all of the programs, as well as no common data collection on the families enrolled and their successes and problems, also precluded any objective "outcome" assessments for the programs' efforts.

Notwithstanding these significant limitations, however, the Commission is able to offer some commentary reflective of the programs' effectiveness. At each of the programs, program directors, parenting aides, and volunteers offered their self-assessments of their program's overall effectiveness, as well as its effectiveness with individual families. Additionally, Commission staff solicited parent assessments of the programs from the 25 families in our second sample.[7] Other commentary related to the programs' effectiveness is drawn from on-site data collection related to operational program standards, the adequacy of programs' staffing and budgets to meet families' needs, and the accountability of the safety net and risk management features of the programs.

Overview

As detailed in this chapter, self-assessments of the programs by the program directors and parenting aides and volunteers were uniformly positive. The 25 parents interviewed by Commission staff also gave the programs high marks. These self-assessments generally matched the assessments of Commission staff who visited the programs. Although certain operational problems tended to be common among most programs and two programs, in particular, appeared to suffer from more serious operational difficulties, Commission staff were impressed by the dedication of program staff to the families, as well as their success in making many concrete and measurable positive changes in the lives of the parents and children they served.

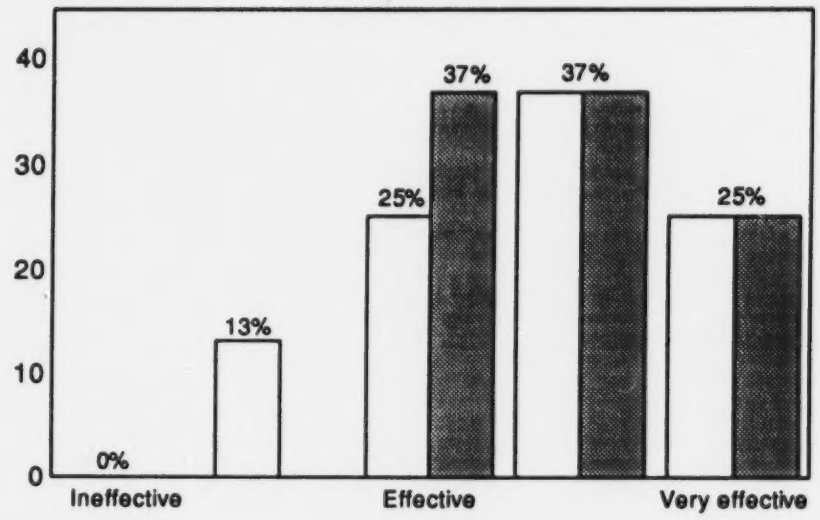
Especially noteworthy were the immediate benefits accrued by many of the enrolled families who moved to more adequate housing, who were assured needed assistance and guidance in preparing more nutritious meals, and who obtained needed medical and mental health services. Program staff also reported that many of the younger children have made clear-cut gains in language development, small and large motor coordination, attention spans, and social skills as they gained access through the assistance of parenting aides and volunteers to early intervention and other preschool programs. In three programs, supportive housing/foster family placements also afforded some families with a level of supervision and services that provided a secure safety net for their children.

Notwithstanding these important contributions of the parenting programs to the well-being and safety of the families, however, the pro-

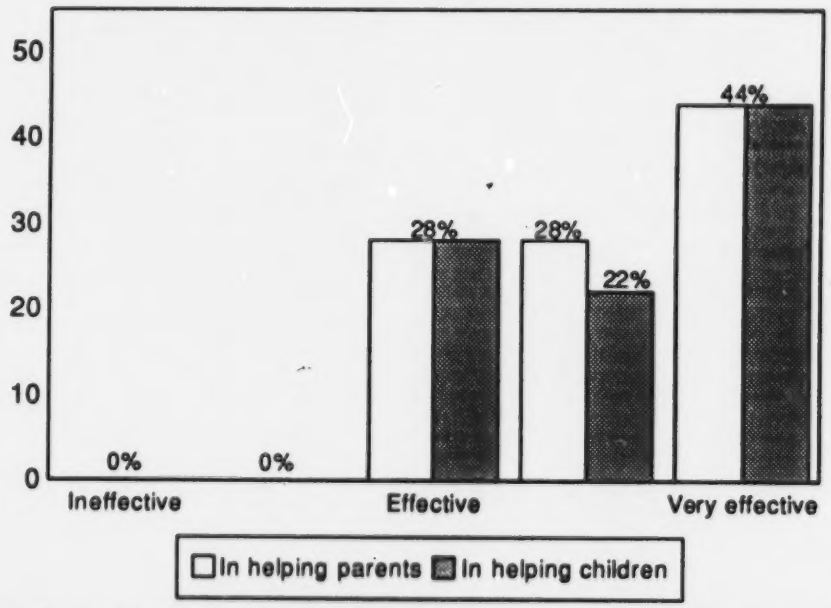
[7] Although three of the eight programs reported conducting consumer evaluation surveys, collected data from these surveys were usually very limited and not sufficient for analysis.

Figure 20: Ratings of Program Effectiveness

By Program Directors
(N = 8)



By Parenting Aides and Volunteers
(N = 18)



*The 18 aides/volunteers represented 6 of the 8 programs and accompanied Commission staff on visits to 25 of their enrolled families.

grams also had their limitations. All operated informally, and the institution of program standards for treatment/service plans, progress notes, and communication and coordination with other agencies was clearly needed by most of the programs. More critically, more formal risk management protocols, designed to assure greater accountability and oversight by senior agency administrators and boards of directors of the risk of abuse and neglect to individual children, were needed by all programs. Despite their short-term successes, most of the programs also operated on extremely sparse budgets and had questionable access to continued stable long-term funding. Most of the programs will require both greater and more stable funding if they are to continue to provide quality services for the extended periods of time that these families will require.

In summary, on most available indicators, the parenting programs received high marks for their short-term gains with families. At the same time, specific improvements in some aspects of the programs' daily operations, the enhancement and stabilization of their funding, and the development of more accountable risk management protocols will be critical for these programs long term.

It is also important to emphasize that, for most of the parents enrolled, parenting programs helped them to compensate for their cognitive limitations, but they did not change them. Reflective of this essential fact, program staff assessed few of the parents as likely to "graduate" from their programs any time in the near future. Thus, like most services to persons with mental retardation, the services of the parenting programs must be recognized and funded as long-term services if the objective of holding natural families together is to be maintained.

Self-Assessments by Program Directors and Staff

Commission staff asked program directors to rate the effectiveness of their programs from the perspective of *all* enrolled families and from the perspective of the 41 families in the Commission's initial sample. In addition, paid parenting aides or volunteers were asked to assess the effectiveness of the program for the 25 families in the second sample.

For all assessments, respondents were asked to provide separate effectiveness ratings for the programs' helpfulness to the parents and to the children. All ratings were made on a five-point scale, where "1" indicated ineffective, "3" indicated effective, and "5" indicated very effective.

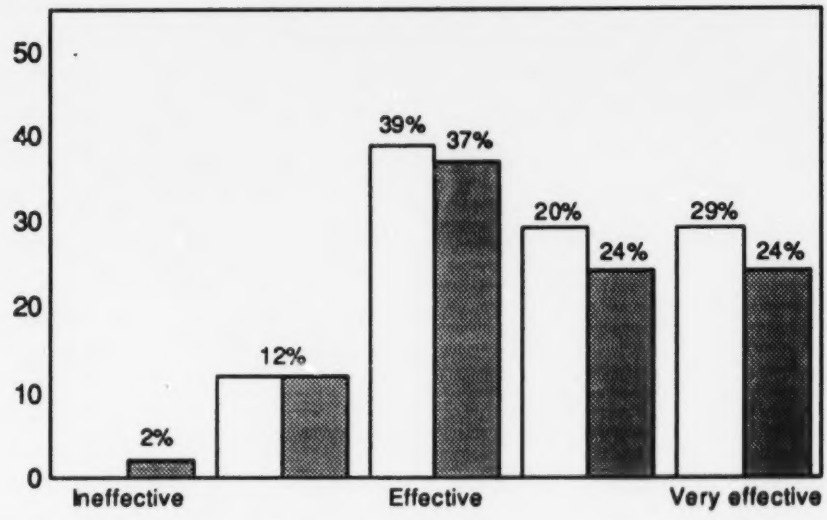
All of these self-assessments resulted in generally positive ratings of the programs' effectiveness, with less than effective ratings usually assigned to fewer than 15% of the families in either of the two Commission samples. At the same time, the effectiveness ratings across the eight programs and among their enrolled families varied across the five-point scale, and as a general rule, "5" or "very effective" ratings were awarded to only about 25% of the families served.

As shown in Figure 20, program directors' overall assessments of their programs' effectiveness in helping the children in the enrolled families were uniformly high, with five of the eight directors giving their programs a rating of "4" (three programs) or "5" (two programs) and no director giving his or her program a less-than-effective rating. Program directors' overall ratings for their programs' effectiveness in helping the parents were slightly less positive, with one program director rating the program as less than effective with a "2" rating, but five of the eight directors awarded "4" (three programs) or "5" ratings (two programs) in this area as well.

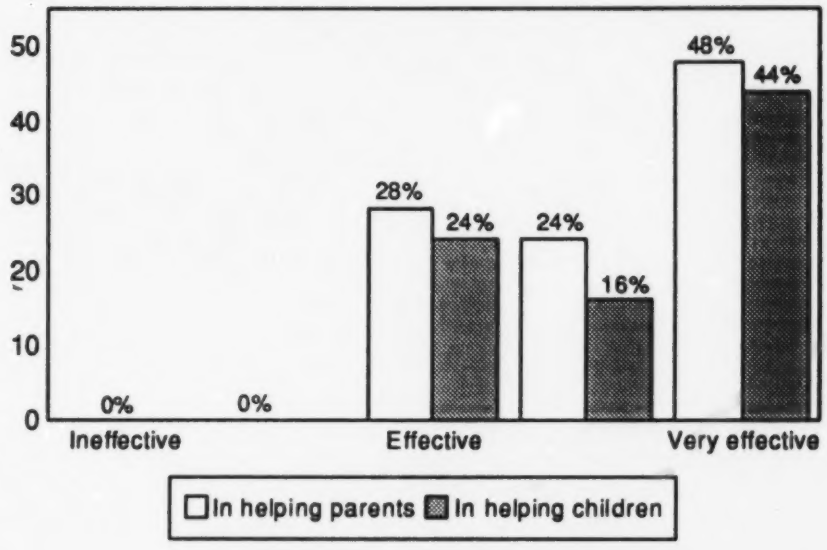
When program directors were later asked to provide effectiveness ratings for each of the 41 families in the Commission's initial sample, their ratings corresponded to their overall positive program assessments, although these rat-

Figure 21: Ratings of Program Effectiveness For Individual Families

As Assigned by Program Directors
(N = 41 Families)*



As Assigned by Aides/Volunteers
(N = 25 Families)*



*Directors assessed program effectiveness for each of the 41 families in the initial sample. Aides/volunteers assessed program effectiveness for each of the 25 families in the second sample.

ings reflected the variable success of the programs with individual families (Figure 21). For example, in terms of helping the children, directors rated their programs as more than effective for 48% of the 41 families. In contrast, directors rated their programs as less than effective in helping the children in 14% of the families, with 12% of the families receiving a "2" rating and one family (2%) receiving a "1" rating. Program directors gave almost identical ratings to the effectiveness of the programs in helping the parents, although no "1" ratings were given.

On the return visits to the programs, Commission staff visited the homes of the 25 families accompanied by the paid staff person or volunteer who was working with the family. In total, 18 different staff or volunteers accompanied Commission staff on these visits. As with the program directors, these staff and volunteers were asked to assess both the overall effectiveness of their programs and their effectiveness in helping the individual families visited. Assessments by these front-line staff tended to be consistent with, if slightly more positive than, those of the program directors.[8]

Front-line parenting aides and volunteers at all programs gave high overall ratings of the programs' effectiveness. Nearly half of these front-line staff (44%) gave their programs an overall "5" or "very effective" rating in helping both the children and the parents, and no front-line staff person gave his or her program an overall rating of less than "3" or "effective." Front-line staff gave their programs similarly high ratings in helping the 25 individual families visited. Front-line staff and volunteers gave "4" or "5" ratings for the programs' effectiveness in helping parents in 72% of the families. Front-line staff also assigned these high ratings for the programs' effectiveness in helping children in 60% of the families. Of note, no front-line staff person indicated that his or her program had been less than effective in assisting any of the 25 families visited.

Continued Assistance Needed by Most Parents Served

For most families, these overall high marks of the programs' effectiveness, however, did not reflect program staff's belief that the family would soon be ready to "graduate" from the services of the parenting program. Only 5 of the 25 families (20%) were judged by their aide or volunteer as likely to be ready to graduate within a year or two. Forty-four percent (44%) of the families were appraised as needing help *even after their children reached adulthood*; another 20% were appraised as needing help *until their children reached adulthood.*

Parenting aides and volunteers also acknowledged that all does go well day-to-day for many of the families served and that ongoing obstacles to their effectiveness are to be expected with the job. When asked to provide specific examples of ongoing problems, aides and volunteers provided a considerable list (Figure 22), with many comments centering on the parents' periodic or ongoing resistiveness toward services. These comments were also consistent with the generally high reported family drop-out rates of most of the programs. Although some programs had markedly higher drop-out rates, most programs "lost" one family for every two to three it successfully enrolled for at least one year.

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[8] A likely explanation for the slightly more positive rating of the front-line staff may be the "self-selection" process for the 25 families visited. As noted earlier, the Commission staff only visited families who consented to visits. Although these families shared a common profile with the larger initial Commission sample of 41 families, a larger percentage of the families visited had been enrolled in the parenting programs for more than one year, and as a group, these families tended to be more compliant and committed to the parenting programs.

Sharyl D.

Ms. D. is a 27-year-old mildly mentally retarded mother of three children, Cindy, Paul, and Barbara, ages 9, 6, and 4, respectively. As a child, Ms. D. was abused, and as an adult, she has often become involved in unstable relationships marred by domestic violence.

All of the children are reportedly well-behaved, and they also play together nicely. Cindy is reportedly doing well in school, but Paul has been diagnosed as mildly mentally retarded and learning disabled. Barbara is not yet enrolled in school, but program staff report that she appears to have no disabilities.

Over time, a number of allegations of neglect have been filed against Ms. D., and all three children have been on local child protective services caseloads at one time or another. Program staff reported that while Ms. D. usually provides the best she can for her children, she does not always know their whereabouts, and there are persistent questions about how well she supervises their daily activities. Ms. D. also continues to need substantial help in ensuring appropriate nutrition and discipline for her children.

Ms. D. spends her day assisting Cindy and Paul in getting ready for school, doing housework and shopping, and babysitting her neighbors' children free of charge. On weekends, she often takes her children on outings to the zoo, parks, and restaurants.

In addition to case management services, Ms. D. receives 17 hours of service each week from the senior volunteer of the parenting program. The volunteer assists Ms. D. in household chores, parenting training, attending medical appointments, and contacting school programs. Ms. D. also usually attends the weekly parenting class.

Ms. D. is reportedly very committed to the parenting program, and her volunteer reports that she has made progress in her housekeeping skills, in getting her children off to school, and in attending parenting classes. Despite this progress, however, Ms. D. needs significant training in providing adequate nutrition and appropriate discipline for her children, and program staff believe that she will continue to need significant support and assistance as long as the children are at home.

Figure 22: Volunteers/Parenting Aides Share Their Difficulties in Working with Families

. . . when mothers do not want help and are noncompliant.

. . . when her husband interferes, she can be easily influenced and resist suggestions.

. . . different parenting styles can make it difficult.

. . . when trying to get parents to understand and to do things.

. . . sometimes parents are untrustworthy and resistive of staff; they would prefer to have staff perform tasks while they watch TV.

. . . when parents do not get up in the morning and attend to their children's needs.

In short, the high self-assessment ratings of the programs by their directors and their front-line staff must be interpreted in the context of the reports of program staff that most of the families will continue to need substantial assistance and support long term and that many families who enroll in their programs drop out after a short time in services.

The Parents' Evaluations

In visiting with the 25 families, Commission staff also solicited their opinions of the help they received from the parenting aide/volunteer, as well as additional help or services they needed, but were not getting. The parents' comments about their aides and volunteers were universally positive, and many were also very specific in identifying the assistance offered them.

Another striking aspect of the parents' comments was their consistent reference to their aides or volunteers more as mothers' helpers and friends, than as teachers. Although some parents specifically identified a skill they had learned to do or had learned to do better with the assistance of their aides or volunteers, many more parents spoke of their aides or volunteers as valuable "assistants," who made parenting and household chores manageable.

[She] helps cook and teaches me how to care for the baby. I need a lot of help with cooking.

[She helps] by listening to me and helping with shopping, cooking, and budgeting.

[She] helps me with my kids.

[She] tells me how to take care of the baby. She tells me about being pregnant.

[She] plays with the kids so I can get work done.

She's sweet; she's like a friend. I like talking with her.

She's helping me potty train my son.

I don't feel so upset and anxious after I talk with [my volunteer]. I get upset easily, but I have to learn to stay calm.

Talking with [my aide] helps. I spend more time with my children.

She tells the children they need to clean up after playing.

[She] helps me with everything—parenting, taking care of my babies, shopping, cooking, appointments.

[She is] teaching me to bathe my baby.

[She] helps me with my children. She teaches me to be a good parent. I couldn't manage without her.

[She] explains things, encourages and supports me.

When asked if there was additional help they needed, many of the parents visited (66%) offered no suggestions, but the remaining one-third asked for a variety of other services.

[I] want to go to school and learn more so I can teach my child.

[I] need someone to come in one time a week to clean the house. I also need someone to baby-sit at least one night a week.

[I need] transportation to doctors' appointments.

[I] would like to find a recreation program for my son. I would also like respite services.

I want a new apartment and a new school for my son.

I want to learn to sew.

I wish that we could live by ourselves [instead of in a supportive apartment] and that we had more money.

Program Operations

From an operational perspective, the eight programs were characterized both by their variability and their informality. As discussed in the previous chapter, the sponsoring agencies of the eight programs had not held their parenting programs to the basic operational criteria of the other certified programs they sponsored (Figure 23). Perhaps due to their demonstration nature, their short-term funding, and/or the lack of any state certification requirements, almost all of the parenting programs tended to have loose standards for treatment and service planning, and especially the statement of specific treatment/service objectives, regular progress notes by front-line staff, and formal reviews of the families' progress or ongoing difficulties.

Figure 23: Limitations of Programs

- ✓ Few expectations for operational standards
  - Admission procedures
  - Service planning
  - Progress notes
  - Service reviews
- ✓ Inadequate funding
- ✓ No assurances for long-term funding

Similarly, standards for ongoing communication and coordination with other community service providers working with their enrolled families was a weak link for many of the programs. Most seriously, relationships between the parenting programs and local child protective and preventive services were conflicted in most of the communities visited. Although Commission staff came to appreciate the intricacies and difficulties of these relationships throughout the course of this evaluation, it was equally apparent that smooth, predictable, and accountable communication between parenting programs and local child protective and preventive services, as well as other community agencies, was vital to the safety and well-being of the children and the parents enrolled in their programs. Thus, the need to formalize and strengthen the parenting programs' standards governing these relationships is great.

Jodie C. and Russell L.

Ms. C. and Mr. L., are both in their mid-thirties. They share a home with Mr. L.'s mother, with whom Mr. L. has lived most of his life. Ms. C. and Mr. L., who are not married, also have a 1-year-old daughter, Stephanie, who lives in a foster care home. Stephanie has severe cerebral palsy and her right side is paralyzed. According to program staff, Stephanie has never cried, and she will most likely never walk or talk. At the time of the Commission's visit, Stephanie had already moved onto her second foster home.

Unlike Mr. L., Ms. C. had a long history of out-of-home placements as a child. At the age of four she was placed in foster care. Later she moved from foster home to foster home; at age 8, she moved to one state institution, and then at age 16, to another institution. At age 17, Ms. C. moved to a community residence, which she left four years later when she married. Ms. C.'s marriage, disrupted by domestic violence, lasted only four months.

The parenting program staff could provide little information about Ms. C.'s life in the interim between her brief marriage and her relationship with Mr. L., but they did report that Mr. L. and Ms. C. have been together for three years and that they had been enrolled in the parenting program for six months at the time of the Commission's review. Reportedly, Ms. C. and Mr. L. joined the program primarily to regain custody of their daughter, Stephanie, who was removed at birth due to "anticipatory neglect."

Mr. L. has held a full-time job since 1975 (age 22) with the local town. Ms. C., who is not employed, spends her days shopping, visiting friends, and going to activities at the parenting program. According to the parenting program staff, Ms. C. and Mr. L. are very social. They are members of a weekly bowling league, and they frequently eat out with friends.

At the time of the Commission's visit, Ms. C. and Mr. L. were receiving about six hours of services weekly from the parenting program. The parenting program volunteer supervises two-hour visits between Stephanie and her parents twice each month in their home, and also provides case management services. Ms. C. also attends two one-hour individualized parenting classes each week conducted by her volunteer. In addition to services from the parenting program, Ms. C. and Mr. L. attend Parents' Anonymous meetings, and they receive legal advocacy and counselling services.

By all accounts, Ms. C. and Mr. L. are very committed to the parenting program and motivated to do whatever they can to have Stephanie home with them soon. The program staff support this goal and strongly believe that, despite Stephanie's physical and mental disabilities, Ms. C. and Mr. L. can appropriately care for her.

Most programs also had flexible admission criteria, which generally opened admission to any parent with a cognitive limitation who was referred or who personally requested admission. The director of only one of the programs spoke explicitly about limiting program enrollment to parents whom she believed the program had a reasonable potential to help. Most program directors, in contrast, limited enrollment primarily based on their program's capacity. These latter programs typically served a number of families whose commitment to the program was marginal and whose children remained in ongoing jeopardy of neglect and/or abuse, despite the program's intervention.

Most of the sponsoring agencies of the parenting programs recognized these operational shortcomings of their programs and were moving to make necessary changes to bring these programs up to the standards they held for their other services. Simultaneously, however, it was clear that resources also played a substantial role in the informality of most of the programs' operations. Surviving on sparse budgets, most of the programs had compromised the formality of program operations for more staff time devoted to direct family services. Without additional resources, it is questionable whether these programs will be able to meet accepted standards for treatment/service planning, progress notes, and regular progress reviews or communication with other agencies, including their local child protective and preventive services.

Program Funding

Another obvious need of the programs was a stable source of funding, and in almost all cases, a substantially increased per family funding allowance. These demonstration programs were conceived with an expectation that volunteers, paid the marginal federal stipend allowance of $2.35/hour, would provide the bulk of the direct services to individual families. As documented in this report, most of the sponsoring agencies soon determined that this "volunteer" staffing could not constitute the backbone of their programs.

Paid parenting aides, usually without significant professional education or training, provided quality staffing at most of the programs. The Commission came to question, however, whether the wages of the parenting aides, ranging from minimum wage to $6.50/hour (at one program), were commensurate with the responsibilities and demands of their jobs for independent judgment, initiative, and competence. The jobs of parenting aides were more comparable to those of intensive case managers, yet the highest paid parenting aide in the eight programs received an annual salary of only $15,000 and the lowest paid received an annual salary of only $8,840.

It was also apparent at most programs that most families would have benefited from more hours of service weekly, but that available staffing limited the assistance and support that could be provided. Additionally, most program staff recognized that continued service to their enrolled families, as their typically very young children entered grade school and later middle school and high school, would necessitate an augmenting of their services. Most apparently, most of the children would need assistance with school work that their parents may not be able to provide.

Program directors and front-line staff also uniformly acknowledged that the social isolation of the families, and especially the children from other children in their communities, was a significant problem which their programs, given current resources, could address in only a limited way. This outstanding unmet service need would become only more critical as children grew up and their healthy development depended on satisfactory friendships with peers, as well as their parents.

Finally, as reported above, prompt "graduation" from services was not a realistic goal for most of the enrolled families. While program

Figure 24: Trouble Spots for Programs

- Relationships with local child protective/preventive services
- When to make calls to the Child Abuse Hotline
- What to do when families drop out
- Clear guidelines for reporting serious incidents to agency administrative/board directors

staff uniformly reported that most parents gained parenting skills and confidence through their programs, they also indicated that for most of their families, long-term assistance and support would be needed. Success, therefore, would be measured more by the continued enrollment and progress of families, not program graduation. This reality reinforced the importance of stable, long-term funding for programs serving these families. It further suggested that waiting lists of parents with mental retardation, maintained by most of the parenting programs, could be reached only if the programs were afforded additional resources.

In summary, stable and enriched funding appeared to be imperative to the continued operation of the eight parenting programs. Upon termination of the Developmental Disabilities Planning Council demonstration funding grants, it appeared that most of the programs would need to consider whether alternative funding sources could meet both of these criteria. Continuing these programs with marginal and temporary funding would make it extremely unlikely that the programs would be able to shore up their existing operational limitations, much less extend their services to meet the additional needs of the families, as their children passed through toddlerhood.

Risk Management

Across all of the parenting programs visited, the Commission was perhaps most struck by the enormous undertaking of their sponsoring agencies in agreeing, with the assistance of a relatively small grant from the Developmental Disabilities Planning Council, to reach out to parents with mental retardation and cognitive limitations in their communities. Serving these parents and their children placed these agencies on the frontier of new areas of service delivery, where standard criteria for "good" programs are still undeveloped, and the dangers of unpreventable or unintended human error may be grave.

The commitment, resourcefulness, and courage of these sponsoring agencies and their parenting program directors and staff in meeting these challenges were often remarkable. Simultaneously, however, the directors of all of the parenting programs frankly acknowledged that their services and benefits carried with them a heavy ongoing burden of potential risk to children. Each of the programs visited had developed its own—often unspoken and always unwritten—method for managing this risk (Figure 24). In some programs, with some families, these informal systems worked better than in others. In all instances, their effectiveness was vulnerably dependent on the judgment of individual front-line aides or volunteers and program directors, who made risk assessments without the advantage of standardized assessment tools and often without the reliable record of regular record notes charting the families' historical progress toward treatment/service plan objectives.

A few of the programs had taken the formal position that they did not want to be any part of a decision to remove children from their parents. In particular, they sought to avoid ever being a record source for local child protective and preventive services, but essentially kept no substantive record notes of their involvement with enrolled families. More typically, however, program directors, aides, and volunteers wrestled with "risk management" informally, as specific family crises caused them to reevaluate whether maintaining the family unit was truly in the best interest of the children.

None of the programs visited had developed formal risk management protocols with the required oversight of senior agency administrators and boards of directors to govern their interventions with individual families and their communications with local child preventive and protective services. Although the absence of risk management protocols was not unreasonable, given the incipient nature of their services to parents with mental retardation and cognitive limitations, putting such procedures in place, in coordination with local child protective and preventive services officials, was clearly a pressing imperative for all the programs.

Chapter VI
Conclusions and Recommendations

As illustrated in this report, heterogeneity seemed to be the trademark of the eight parenting programs. Although the NYS Developmental Disabilities Planning Council had expected the eight programs to rely on a common service delivery model, heavily dependent on senior citizen volunteers, the Commission found eight unique programs. Each program was also learning by doing, and making significant changes in how they served families as they moved ahead. Formal recordkeeping and service outcome data were also not strong features of any of the programs. To the extent that the DDPC intended to evaluate the effectiveness of either the "model" or the programs' actual outcomes with families, these expectations appear not to have been absorbed by any of the programs.

The differences in the programs, the absence of historical recordkeeping, and the changes the programs were undergoing made conducting a formal comparative evaluation of the programs difficult. Nonetheless, through site visits, reviews of case records and fiscal reports, and interviews with program directors, parenting aides, volunteers, and the parents themselves, the Commission was able to learn much about the benefits, as well as the needs and difficulties, of the programs.

Larger, better-funded agencies were able to offer important advantages, including easy access to agency-sponsored preschool and supportive housing programs.

Adequate, Long-Term Funding Is Essential

As noted in this report, the Commission discovered that the programs operated with very different resources. The annual budgets of the programs' sponsoring agencies ranged from less than $2 million to over $25 million, and larger, better-funded agencies were able to offer important advantages, including easy access to agency-sponsored preschool and supportive housing programs.

Annual per family funding ranged from less than $5,000 at one program to over $10,000 at another.

Funding for the parenting programs themselves also varied by more than 100%, largely because some agencies had successfully leveraged non-DDPC funding sources, including OMRDD grants and Medicaid case management funds, to supplement their grants from the Council. FY 1991-1992 funding ranged from under $60,000 to over $100,000. And, although better-funded programs usually also served more families, this was not always the case, and annual per family funding ranged from less than $5,000 per family at one program to over $11,000 per family at another.

These differences in available resources among the parenting programs took on an even greater significance as the directors of all the programs told the Commission that their existing funding was not adequate to meet the needs of many of the families they served and that most of their families would need intensive services for years to come. Program directors, as well as parenting aides and volunteers, noted that they needed smaller caseloads and more time to provide in-home services for a significant percentage of the families enrolled.

The Commission, like most of the sponsoring agencies, came to appreciate that while volunteers could be a valuable asset to parenting programs, paid parenting aides were also essential.

Program directors assessed 74% of the 41 families in the sample as having at least one significant unmet service need, and they estimated that two-thirds of the families would require services at least until their children reached adulthood. Program directors affirmed that these programs assisted the parents in functioning more effectively with their limitations, but that the programs did not, *in most cases*, make enduring changes in the capacities of the parents to meet the changing challenges of raising children on their own.

Whether or not these programs could be effectively staffed primarily with volunteers, as originally proposed, was also a central resource issue. Four of the eight programs found that their programs could not function with a primary reliance on volunteers to assist families. Of the other four programs which relied extensively on volunteers, one had closed during its first year, another served only five families, and one relied extensively on enriched foster care placements for half of their enrolled families.

The Commission, like most of the sponsoring agencies, came to appreciate that while volunteers could be a valuable asset to parenting programs, paid parenting aides were also essential. As delineated in the many family vignettes in this report, many of the families served had multiple problems, which would be difficult for even the most competent and dedicated volunteer to address. Other families needed more hours of service weekly than most volunteers would be able to offer.

These Are Challenging Programs

The experiences of the programs also suggested that these were not easy programs to operationalize. Almost all of the programs required funding for a four to six month start-up period before they began to serve families; one program closed within the first year; and one other program remained very small, serving only five families.

It became apparent that the programs' focus on in-home service delivery required them to be very sensitive to individualization of their services. Selecting the right people to assume this intrusive service delivery role, matching aides and volunteers with families, and keeping families engaged in services were common initial, and in some cases ongoing, problems for the parenting programs.

Although parent training remained the goal, usually the majority of staff time was spent in direct family assistance and support.

Program directors also reported that the cognitive limitations of the parents presented real challenges as they attempted to construct viable parenting teaching and learning situations. Although all programs offered parenting classes, most found that in-home teaching—with a heavy reliance on aides and volunteers doing tasks

alongside of the parents—was the most successful model. Additionally, almost all programs spent more time in direct assistance to families in finding adequate housing, in transporting parents to stores and doctors, in relating with teachers, in helping with cooking, cleaning, and childcare than they had originally intended. As a result, although parent training remained the goal, usually the majority of staff time was spent in direct family assistance and support.

High Turnover Rates in Enrolled Families Are Common

Despite their start-up difficulties, however, almost all programs were operating at maximum capacity by the fall of 1991. In fact, most programs had at least one family on a waiting list. It seemed that families headed by at least one parent who was mentally retarded were fairly common in all of the communities studied, and that once the parenting programs' services became known, referrals were plentiful.

If program referrals were plentiful, however, so were program discharges. Five of the eight programs had annual dropout to enrollment rates of over 40%. The parents' reasons for dropping out varied, but most centered on the parents' reluctance to take outside direction or their discomfort with the intrusiveness of in-home services. Keeping families engaged and interested in services was an ongoing service delivery issue for all of the programs.

Keeping families engaged in services was an ongoing issue for all of the programs.

Although many factors influenced the dropout rates of the programs, their informal admission practices certainly played a role. Referred families who wanted services were usually accepted, if space was available. Formal assessments, including psychological testing and daily living or parenting functional assessments, were not usually critical steps in the admission decision-making process.

Many parents had avoided the label, mentally retarded, for years, and they were not willing to accept it now—just to enroll in a parenting program.

While the programs' assessment policies could be partially attributed to their limited clinical resources—they also reflected the aversion of many of the parents who presented for admission to any formal testing. Commission staff were told that many parents had avoided the label, mentally retarded, for years, and they were not willing to accept it now—just to enroll in a parenting program. Many of the parents were also insecure about their parenting skills, and program staff perceptively judged that doing formal assessments of these skills would not be well-received.

Notwithstanding these reasonable explanations, however, the informal assessment practices of many of the programs often resulted in programs not having a full understanding of the parents' abilities and limitations. It also sometimes resulted in programs enrolling parents with limited commitment to the parenting programs or to making real changes in their lives.

Some Program Standards Are Needed

Keeping in mind that the parenting programs were small demonstration projects not constrained by state certification standards, it was perhaps not surprising that the Commission found that formal service planning procedures were not strong features of most of the programs. Records of many of the 41 families in the

initial sample did not include service plans, specific service objectives, or progress notes. The absence of regular progress notes was particularly unfortunate, for without them, it was virtually impossible to chart the historical course of the families served.

Where progress notes were not present, program directors usually explained that they did not have rigorous expectations for aides or volunteers to enter regular notes. Three program directors added that they preferred scanty notes, as the availability of few notes made it less likely that their records would be subpoenaed by local child protective or preventive services.

Anecdotal reports strongly suggested that most families were better off as a result of program enrollment.

All of the program directors stated they had regular service plan reviews, but their frequency varied from monthly at one program to annually at two others. Many program directors and their staff also saw the family's service plan more as a paperwork requirement, than as a viable road map for service delivery and progress assessment. Repeatedly, Commission staff heard that families' needs exceeded the program's resources and that day-to-day crises made quarterly or annual service plan objectives sometimes irrelevant. Notwithstanding the legitimacy of these arguments, it was also clear that marginal attention to service plan reviews often left program staff without a clear view of what they had done, what accomplishments the parents had made, or conversely, what problems the parents had not been able to overcome. It also left most programs with a fairly *ad hoc* system for planning resource allocations among their enrolled families.

Another significant disadvantage of the limited recordkeeping at all the programs was that it precluded objective measurement of program success. Given the controversy and cost of these family-based services, evaluation reports relating the outcomes for enrolled families would be valuable tools in formulating future public policy.

Families Derived Apparent Benefits From the Programs

Even in the absence of formal evaluation reports, however, anecdotal commentary by the program staff and the parents strongly suggested that most families were better off as a result of program enrollment. Many families clearly benefited from access to better housing and early intervention preschool programs for their young children, while almost all families enjoyed social opportunities which for some were their only break from very isolated daily lives. Aides and volunteers often became the families' vital life lines to medical service providers and school officials. Finally, and not inconsequentially, the programs offered many of the enrolled parents their first trusted friend in the bureaucracy of social welfare programs.

The programs offered many of the enrolled parents their first trusted friend in the bureaucracy of social welfare programs.

Self-assessments of the programs by the programs' directors, aides, and volunteers were also universally positive. As discussed in the previous chapter, these self-assessments usually resulted in better than effective ratings for the programs in helping both the parents and the children. These positive ratings by program staff were uniformly matched by the parents' own comments. Without exception, the parents in the 25 families visited by the Commission expressed great appreciation for the programs. One must be mindful, however, that these comments came

from the parents who stayed with the programs, and that over one-third of the parents who enrolled in these programs statewide had left the programs, usually due to dissatisfaction with them.

Assuring stable, long-term funding sufficient to meet the needs of families is a baseline requisite for the continuation of each of the programs.

Looking Ahead

These programs, despite their reported benefits, however, also had limitations which required attention and correction.

Rethinking admission criteria in the hopes of reducing drop-out rates and developing cooperative assessment procedures *with the parents* are critical next steps for the programs. Additionally, more effective methods for developing practical service plans *for and with the parents* and for ensuring regular progress notes and service plan reviews will also be important.

Ensuring these program standards is especially critical, given the high risk status of many of the families and the need for ongoing assurances that the children are safe. Parenting aides and volunteers were deeply committed to the families they served, yet few had any substantial training or experience in serving persons with developmental disabilities or in intervening appropriately in situations of possible child abuse or neglect. Given these circumstances, the importance of regular, accountable professional staff reviews of progress and service plans conducted with the parents and the aides/volunteers cannot be overstated.

Each of the programs had also enrolled many families that would require costly services and assistance long term. Many programs recognized that the families' needs for assistance would change markedly as their children became older and that, in many respects, the future would present more, not fewer, challenges. Assuring stable, long-term funding sufficient to meet the needs of families is a baseline requisite for the continuation of each of the programs.

Most programs also suffered from conflicted relationships with local child preventive and protective services. Program staff often became frustrated with preventive workers who seemed to overlook the cognitive limitations of the parents, as the worker recited their litany of expectations; others became angry as preventive workers made demands, but seemed to offer little real hands-on help. With some inevitability, parenting program staff often came to be seen as the "good" caseworkers, whereas the child preventive and protective workers came to be seen as the "bad" caseworkers who threatened to take the parents' children away. Some program directors saw this conflict as helpful; others believed that more could be done, more efficiently and more cost effectively if they were able to achieve a more cooperative and mutually supportive relationship with local child preventive and protective services.

Program staff often became frustrated with preventive workers who seemed to overlook the cognitive limitations of the parents, or who made demands, but seemed to offer little real hands-on help.

When to call the Child Abuse Hotline was also not an easy decision for any of the programs. Parenting program staff had become personally invested with the families, and taking this step was often not perceived as helpful to either the parents or the children. At the same time, however, and particularly in the absence of regular, objective risk assessments of the children, especially in families encountering serious problems, the Commission noted instances where

some required reports to the Hotline either were not made or were made late by the programs, leaving children at unnecessary risk of harm and serious injury.

Some required reports to the Hotline either were not made or were made late by the programs, leaving children at unnecessary risk of harm and serious injury.

Similarly, programs had difficulties deciding what to do when families with problems dropped out. Some routinely called local child preventive and protective services officials; others believed this approach was premature and the families should be given a chance on their own—like other families in the communities. Balancing the parents' rights with the potential risk to the welfare of the children was a universal challenge of the programs.

All of these issues suggest a need for strong risk management protections around the parenting programs, but most of the sponsoring agencies actually assured their parenting programs less risk management oversight than they did for their other programs. As unlicensed and uncertified programs, these parenting programs operated outside many of the established quality assurance mechanisms applicable to their certified programs. The sponsoring agencies also allowed the parenting programs to operate on a more *ad hoc* basis, with little formal or regularly scheduled oversight by agency administrators or boards of directors. While this casualness toward formal quality assurance was somewhat understandable given the demonstration nature of the parenting programs in serving families long term, the need to strengthen overall quality assurance standards, as well as to assure regular, objective risk management assessments for individual families, will be critical.

The review of the programs also raised the inevitable question of the benefits of the programs for the long-term welfare of the children. The Commission's review of the eight parenting programs—over a short period of time—could not answer this question, although it often figured prominently in staff discussions of the programs visited.

There was unequivocal evidence, however, that many of the young children in the families enrolled in the parenting programs had significantly benefited from their intervention. Unfortunately, in a minority of families, the Commission also heard of situations where the presence of the parenting program seemed to delay out-of-home placements of children subject to ongoing neglect and abuse, which neither the parents nor the parenting program were successful in halting. In other instances, children were not in imminent danger, but it was hard not to sometimes question its long-term impact of less severe neglect on their physical, emotional, and cognitive growth. Additionally, there was some anecdotal evidence that older children were considerably more difficult to manage than younger children for parents who are mentally retarded.

Balancing the parents' rights with the potential risk to the welfare of the children was a universal challenge of the programs.

Review statistics indicating that the percentage of children with disabilities increased with the age of the children, as well as the few older children still in the custody of their parents, further reinforce the need for more research directed toward the important question of how the development of children parented by adults

with mental retardation is affected as they approach adolescence and adulthood.

The long-term service role of these programs in meeting the families' needs is also not consistent with existing family support service models. Despite the rhetoric for family preservation, local social services districts are not funded to provide intensive services, except to a small number of families, and then for only relatively short periods of time. Whatever the wisdom of these public policy constraints, they are clearly not realistic for families headed by a parent who is mentally retarded, where assistance is likely to be needed throughout the parenting years.

Recommendations

1. ***Parenting programs serving parents who are mentally retarded should be adequately funded with the realistic expectations that most enrolled parents will need services for many years.***

   - Programs should have sufficient resources to provide at least 10-15 hours of in-home service on average per enrolled family.
   - While volunteers can be valuable resources for these programs, the programs should also have resources for some paid parenting aides.
   - Programs must have resources to provide critical ancillary services, including a 24-hour crisis on-call capacity, transportation, and petty cash to cover emergency family needs.

2. ***Parenting programs for parents who are mentally retarded should ensure that enrolled parents are active partners in service planning.***

   - Programs should have reasonable admission screening procedures, including formal needs assessments of the parents, which are designed to assist the parents and the program staff to work together to develop a practical service plan, with clearly stated and measurable short-term and long-term objectives.
   - Programs should require that parents be actively involved in the assessment process and in using its findings to select personal parenting training objectives.
   - Parents should be actively involved with program staff in reviewing service plans at least quarterly, in providing explicit comments on the progress made and any specific difficulties encountered, and in suggesting specific revision in service plans.

3. ***Parenting programs serving parents who are mentally retarded should have clear standards governing the presence and nature of service plans, regular progress notes, and periodic reviews of progress.***

   These standards should be developed by the program's sponsoring agencies with the participation of the enrolled families and the agency's board of directors and in compliance with basic program guidelines for other family support programs funded by OMRDD. On admission to parenting programs, parents should be informed of how these program standards will affect their services, as well as their ability to access their personal records maintained by the parenting program.

4. ***Agencies sponsoring or funding parenting programs for parents who are mentally retarded should establish formal quality assurance/risk management procedures.***

   These procedures should ensure oversight of the program's effectiveness, its compliance with established program standards, and the appropriate provision of periodic

objective reviews of the safety and well-being of the children in the enrolled families. Quality assurance activities should also include formal reviews of appropriate and timely reporting to the State Child Abuse Hotline, as required by law.

5. ***Parenting programs serving parents who are mentally retarded should establish written service agreements with their local child preventive and protective services governing the program staff's interactions with families who are also on child protective and child preventive caseloads.***

   These formal agreements should ensure that:

   - the parenting program staff and caseworkers from local child preventive services establish cooperative relationships in setting service goals and objectives for the families, in establishing common expectations for the parents, in sharing the service provision role to the families, and in monitoring the progress made with the parents;
   - clear expectations are established for sharing information about the family, that these standards are communicated to the parents, and that these standards are regularly followed by the staff of parenting programs and local child preventive and protective services; and
   - explicit procedures are developed for regular, and at least quarterly, collaborative risk assessments for the children, relying on the State Department of Social Services' official risk assessment tool.

6. ***All paid and volunteer staff of parenting programs serving parents who are mentally retarded should be required to participate in a formal training program which:***

   - provides explicit guidance in assessing the risks which may be present for children in families headed by a parent who is mentally retarded and in tailoring specific interventions to reduce these risks;
   - details the responsibilities of aides and volunteers in making and documenting reports to their supervisors of situations which may warrant a formal report to the Child Abuse Hotline;
   - discusses the cooperative roles and responsibilities of the parenting program and the local child preventive and protective services in serving families in their community; and
   - delineates the incidents and circumstances occurring in families on the rolls of child preventive and protective services which should be promptly reported to their preventive or protective caseworker.

7. ***The NYS Developmental Disabilities Planning Council, in conjunction with the State Department of Social Services, should support additional research which examines the long-term benefits of parenting training programs for children in families headed by one or more parents who are mentally retarded.***

   This research should focus on the long-term effects of these programs on the children's development, health, and safety, but it should also seek to identify the critical characteristics of more successful programs, the adequate funding level for these programs, and the parent and family characteristics which predict positive long-term outcomes for families, including but not limited to the avoidance of out-of-home placements. To the extent possible, this research effort should also attempt to assess the initiatives of other states in developing effective service programs for parents with developmental disabilities and in financing these services.

Appendix A

STATE OF NEW YORK
OFFICE OF MENTAL RETARDATION AND DEVELOPMENTAL DISABILITIES

44 HOLLAND AVENUE • ALBANY • NEW YORK • 12229-0001

ELIN M. HOWE
Commissioner

THOMAS A. MAUL
Executive Deputy Commissioner

June 30, 1993

Clarence J. Sundram
Chairman
Commission on Quality of Care
For the Mentally Disabled
99 Washington Avenue, Suite 1002
Albany, NY 12210

Dear Mr Clarence Sundram:

Thank you for sending me the two draft confidential reports related to the Commission's review of programs regarding parents who are mentally retarded. I am sorry for the delay in a formal response. To assure our prompt input I asked Andy Ulitsky to follow-up and he met with Dr. Nancy K. Ray and staff on June 21, 1993. That meeting and this letter will serve as OMRDD's response to this clearly important issue.

Both reports are very thorough and descriptive and certainly paint a realistic picture of a population we knew existed, but one which we knew little about both quantitatively and qualitatively. We do not dispute the accuracy of any of your data. In terms of the recommendations in the "Programs" piece, we agree that:

(1) parenting programs should be "adequately funded with ... realistic expectations". Any recommendation such as this must of course acknowledge funding availability and the input of our local Consumer Councils who are now very directly involved in both policy and funding decisions.

(2) enrolled parents should be active partners in service planning. In fact, we must assure that as the Councils further develop that they include parents who are mentally retarded (or their advocates) as members to assure first, that this population is known and second, that they have a say in the direction of the program. We are also working with each Council to develop their requests for training curriculum and the issue of

parenting programs will certainly be added. Their ideas will be considered in light of OMRDD's existing training programs, the work of the Family Empowerment and Support Subcommittee and the Interagency Work Group on Parent Education and Support (Judith Avner, Chair). Our entire philosophy now centers around service planning driven by individuals and their families who are mentally retarded or developmentally disabled. Parenting curricula could be generic with presentation techniques varying by student needs.

(3) Parenting programs should have clear standards, and

(4) Agencies providing programs should establish formal quality assurance/risk management procedures.

As connected to #2 above, consumers/families are now also directly involved in the area of monitoring programs via evaluations, standards and consumer satisfaction. OMRDD and the private provider agencies recognize their role in this process as well and, in fact, guidelines are being developed in cooperation with consumers based on six successful prototypes around NYS.

(5) Programs should establish written service agreements with local child preventive and protective services.

It is clear throughout your reports, as well as intuitively obvious, that any of these families could easily involve many other service systems, especially child preventive and protective services. We certainly do not yet have hard statistical projections of the number of such families, but as we proceed we must assure a close partnership with at least the State Department of Social Services (especially in terms of a risk assessment tool). OMRDD will, by the way, review our system to also try to establish how many such parents there are in New York State.

(6) Establish formal training programs for staff. We strongly agree on the need for several training programs based on what the Councils request. For this population, staff must be aware of the tie in with CPS and the need for risk management.

(7) DDPC and DSS should support additional research. OMRDD, though not specified here, is certainly interested in the results of this research and any longitudinal studies regarding both parents and children.

The second paper regarding the "Parents", offers conclusions rather than recommendations. Since these conclusions are based on the same issues, OMRDD supports their content (e.g., the long term nature of these families' needs, strengths of program services and informal supports, access to early intervention preschool programs and supportive housing, etc.).

Overall, the two papers address timely and important topics. I am committed to serving individuals/families who are mentally retarded and developmentally disabled and the descriptions of the demonstration program's staffing, services and evaluations as well as the profiles of the families and children are invaluable to OMRDD as it expands its Consumer Councils and supports to families. We will strive to keep the successful programs going and add this information into next year's Request for Proposals process. It is critical that we recognize the need for a funding process which encourages participation of all State service systems which will inevitably come in contact with these families. I will be glad to share these papers or an abstract with the Statewide Committee on Family Support Services and with each of our local Consumer Councils as soon as you are ready to distribute these as final products. Andy has also sent Nancy a list of all the Councils so that you could add them to your mailing list for the CQC Newsletter.

Again, thank you for the opportunity to add our comments. Please feel free to contact me or Andy to discuss any additional details related to these papers and, more importantly, as you begin on the next steps identified. OMRDD is anxious to address the needs of parents with mental retardation and their children.

Sincerely,

Elin

Elin M. Howe
Commissioner

EMH:AU

cc: Mr. Ulitsky
Dr. Ray

NEW YORK STATE
DEPARTMENT OF SOCIAL SERVICES
40 NORTH PEARL STREET, ALBANY, NEW YORK 12243-0001

Gregory M. Kaladjian
Acting Commissioner

FRANK PUIG
Deputy Commissioner
Division of Services & Community Development

May 10, 1993

Mr. Clarence J. Sundram
Chairman
Commission on Quality of Care
for the Mentally Disabled
99 Washington Avenue, Suite 1002
Albany, New York 12210-2895

Dear Mr. Sundram:

Thank you for your April 6, 1993 correspondence to Acting Commissioner Gregory Kaladjian which transmitted the draft reports entitled:

Parents With Special Needs: A Review of Parents who are Mentally Retarded; and

Serving Parents Who are Mentally Retarded: A Review of Eight Parenting Programs in New York State.

The Department received a grant from New York State Developmental Disabilities Planning Council to help facilitate coordination of social and mental health services, and training for the eight programs which are cited in the latter report. The reports exemplify the challenges parents with developmental disabilities encounter and the various levels of support such families need from our human services system. Although there is much work to be done, the Department is pleased with the accomplishments which have been achieved through our joint program development efforts with the New York State Developmental Disabilities Planning Council (DDPC).

I have shared copies of the report with my staff of the Office of Family and Children Services. Since the reports' recommendations have potential impact on existing child welfare policy and program development activities, I would like to invite your staff to meet with our Policy and Program Development staff to assess the feasibility and potential impact of the recommendations espoused in the report. The Department is currently planning the implementation of several program development activities which may provide opportunities for continuing interagency program development with DDPC. Therefore the scheduling of such a meeting in the next several weeks would be quite timely. Your staff should contact Mr. David Peters, Director of the Bureau of Program Development at 474-9437 to schedule the meeting.

AN EQUAL OPPORTUNITY/AFFIRMATIVE ACTION EMPLOYER

On behalf of the Department, I wish to express my appreciation for your interest in and support for quality services for individuals and families with developmental disabilities.

Sincerely,

Frank Puig

Frank Puig
Deputy Commissioner
Division of Services & Community
Development

cc: James Purcell

New York State
Office of
ADVOCATE for the DISABLED
EMPIRE STATE PLAZA ALBANY, NY 12223-0001

Frances G. Berko, J.D., M.A.
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April 13, 1993

Honorable Clarence Sundram, Chairman
Commission on Quality of Care for the
Mentally Disabled
One Commerce Plaza, 10th Floor
Albany, NY 12223

Dear Chairman Sundram:

I have reviewed the confidential drafts of Parents with Special Needs: A Review of Parents Who Are Mentally Retarded and Serving Parents Who Are Mentally Retarded: A Review of Eight Parenting Programs in New York State. The thoroughness of the fact-finding which Dr. Nancy K. Ray and her team demonstrated in their evaluation of these eight DDPC-funded projects has led me to wonder why additional recommendations were not included.

Primary among these is concern about alternatives which need further exploration to appropriately serve this population in the future. The reports point out the most of the populations served by the existing programs have been diagnosed as having mild mental retardation, often in combination with other debilitating factors. Since attention to the needs of persons with mild mental retardation has been minimal, and often not even identified, throughout this state's human services delivery systems, and since, except for such diagnosis, the profiles of the people served appear to be identical to persons served through DSS Protective Services' family intervention programs, DSS's and OMH's federally funded Home Builders projects and less intensive parenting services provided by these and several other state agencies -- none of which do not include formal measurements of the parental cognitive abilities and academic skills -- one is left to wonder:

(a) How many of the parents served by these generic programs also have similar cognitive and/or academic limitations?

(b) Except for being labeled as having "mental retardation", does a clear differentiation exist between the populations served by the DDPC-funded programs and those served by other agencies' parenting services?

(c) Do these other programs also need the recommended personnel training and continuing parenting support?

(d) In view of the fact that at least half of those eligible for the DDPC/OMRDD-funded programs refused to participate, reportedly from unwillingness to acknowledge or re-enforce the label of having a disability, whether the on-going parental supports identified may be more appropriately provided by the generic agencies, like DSS, after adequate personnel training, rather than disability-oriented state agencies, like the DDPC and OMRDD?

Although I realize that any search for answers is clearly beyond the mission and scope of the present report, the facts uncovered indicate a necessity for a recommendation referring these questions to an appropriate interagency body for exploration. Such a referral might even include a review of the mandates, regulations and processes of the now twenty-five year old Child Protective Services.

From the data presented in the reports, I expected to see additional recommendations that would:

- Specify an existing interagency group, not necessarily DDPC, to develop uniform standards;
- Assign the development of permanent funding mechanisms to a specified state agency's existing service continuum, i.e., OMRDD's family support services;
- Identify a strategy or strategies for the prevention of disabilities in the at-risk children of the parents served, such as the development of mechanisms for routine and immediate access to early intervention programs like DOH's IHAP services; and
- Explore, perhaps through the DDPC, the needs of parents who have moderate-to severe mental retardation, physical and/or other developmental disabilities and, if indicated, develop similar demonstration projects for these populations.

Please congratulate Dr. Ray and her staff for the excellent reports. Without their fact-findings and insights, the suggestions made in this letter would not have been possible.

Sincerely,

Frances G. Berko, J.D., M.A.
State Advocate

:ds
cc: I. Mills

The Commission on Quality of Care for the Mentally Disabled is an independent agency responsible for oversight in New York State's mental hygiene system. The Commission also investigates complaints and responds to requests concerning patient/resident care and treatment which cannot be resolved with mental hygiene facilities.

The Commission's statewide toll-free number is for calls from patients/residents of mental hygiene facilities and programs, their families, and other concerned advocates.

Toll-free Number: 1-800-624-4143 (Voice/TDD)

BEST